The NGO Role in Supporting Children Affected by HIV/AIDS: Challenges, Case Studies, and Lessons Learned

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THE CHILD SURVIVAL TECHNICAL SUPPORT PROJECT

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Acronyms

AFA	Ark Foundation of Africa
CAC	Community AIDS Committee
CARE	Cooperative for Assistance and Relief Everywhere, Inc.
CBO	community-based organization
CCF	Christian Children's Fund
CHW	community health worker
COPE	community-based options for protection and empowerment
CPC	Country Program Council
CS	child survival
CSTS	Child Survival Technical Support Project
FACT	Family AIDS Caring Trust
FBO	faith-based organization
HACI	Hope for African Children's Initiative
HBC	home-based care
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
IDU	injecting drug user
M&E	monitoring and evaluation
MCDI	Medical Care Development International
MCH	maternal and child health
MED	micro-enterprise and development
MFI	micro-finance institution
NGO	nongovernmental organization
OI	opportunistic infection
OR	operations research
OVC	orphans and other vulnerable children
PLHA	persons living with HIV/AIDS
PPC	Program Policy Council
PSW	psychosocial worker
PVO	Private Voluntary Organization
SBC	social and behavioral change
STI	sexually transmitted infection
TDCSP	Thukela District Child Survival Project
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VAC	Village AIDS Committee
VCT	voluntary counseling and testing
WHO	World Health Organization

Executive Summary

The AIDS epidemic is affecting every region of the world, and in many instances, children and youth are negatively affected. Over the years, many terms have been used to describe this vulnerable segment of society, including "children affected by HIV/AIDS" and "orphans and other vulnerable children (OVC)." Orphans are probably the most visible category of vulnerable children, but it is important to remember that vulnerability begins long before a parent dies.

Regardless of the circumstances that make them vulnerable or the terms used to describe them, vulnerable children have the same basic needs—educational, economic/material, psychological, safety/social protection, and health/nutritional—as other children. Nevertheless, HIV/AIDS disproportionately infects working-age adults in poor societies, leaving many children in the care of their grandmothers or other relatives, to fend for themselves and younger siblings, or to care for sick parents. Additional factors such as the high degree of stigma associated with HIV/AIDS also present challenges in both identifying and meeting the needs of affected children.

What roles can nongovernmental organizations (NGOs) play? NGOs have always demonstrated a strong commitment to community mobilization and empowerment. This close rapport with communities makes them the perfect link between vulnerable members of society and the systems and structures that can support them. When dealing with children and youth, some NGOs might be tempted to rely on the traditional "child survival" model. However, this model requires significant modifications in order to address the multi-faceted problems faced by children affected by HIV/AIDS. Extending program activities beyond children under the age of 5 and their biological mothers is just one such adaptation.

This state-of-the-art paper consolidates information from various sources and provides NGOs with an easy reference on current thinking related to children affected by HIV/AIDS. It discusses roles that NGOs can play, as well as principles for developing programs to reach vulnerable children, families, and communities in AIDS-affected societies.

In developing effective responses, it is important to 1) identify needs collaboratively with children and local stakeholders, 2) be clear in terms of who will be targeted, and 3) determine appropriate areas of action that bolster existing mechanisms of support. Notably, the international community embraces key programming principles such as strengthening the protection and care of vulnerable children within their extended families, ensuring the full involvement of young people as part of the solution, and focusing on the most vulnerable children and communities, not only those orphaned by AIDS. There is a wealth of experiences within the NGO community that supports these guiding principles. Although there is an increasing amount of documentation on NGO and grassroots initiatives for children affected by HIV/AIDS, few documents are written specifically for an NGO audience. This paper highlights examples from current NGO efforts at different levels—from child- or household-focused interventions in a small set of communities to multinational NGO partnerships—and presents them in the form of brief "Field Snapshots" and more-detailed case studies that summarize key approaches, challenges, and lessons learned.

In an effort to keep pace with the epidemic, many NGOs are beginning to consider scaling up what they are currently doing. However, before doing so, it is important to determine the effectiveness and impact of their interventions. This paper highlights key monitoring and evaluation (M&E) considerations based on the following M&E challenges faced by many NGOs: identifying relevant and useful indicators, assessing quality of care and service delivery, and designing approaches to assess the effectiveness or impact of interventions. Cost analysis is another important aspect of project M&E that is often lacking, despite its relevance to sustainability and scale up of activities and impact.

There is tremendous pressure for programs and services to be taken to scale, but there is no clear-cut formula for NGOs to follow. However, when one examines interventions that have been successfully taken to scale, the following factors are usually present: 1) appropriate selection of interventions; 2) an enabling environment for expanded action and impact; 3) documentation of implementation steps, processes, and lessons learned; 4) mechanisms to ensure quality; and 5) clear definition of expected roles for all stakeholders. Each of these dimensions is discussed in Section VII of this paper.

This document does not provide all the answers, but it will hopefully provide insight and guidance on ways that NGOs can fine-tune, test, or expand their efforts to improve the lives of children, families, and communities affected by HIV/AIDS. At times, we might feel overwhelmed by the sheer magnitude of need. However, every NGO initiative, no matter how small, has the potential to foster hope and a sense of self-determination in our most vulnerable members of society. Every child—whether living in a large metropolitan area or a remote rural village—is deserving of that right.

I. Introduction

I.1 NGO roles in the fight against HIV/AIDS

Think back to your childhood. Your memories of school, fun times with friends and family, or the hopes and dreams you had for the future. Now, introduce HIV/AIDS into the picture. What would your life have been like if you, your family, and/or your community was affected by HIV/AIDS?

Individuals affected by HIV/AIDS are more than statistics that we read about in a newspaper or journal article or learn about in a documentary film. The face of HIV/AIDS is very familiar to some children. It is mothers and fathers, aunts and uncles, and brothers and sisters. It is teachers, friends, and others close to them.

Children are affected by the AIDS epidemic in many different ways, including being infected themselves, having sick family members, being the object of stigma, being unable to attend school, and lacking access to adequate food due to the worsening economic status of their family. The numbers of orphans due to HIV/AIDS are overwhelming, as shown in Table 1.

In Africa, the number of children orphaned annually in 2005 will increase by five million and by another four million by 2010. According to DHS surveys, the number of orphans in Tanzania grew by almost 400,000 between 1992 and 1999. Kenya's orphan population grew the same amount in only five years. Their findings further suggest that most of these children have been orphaned directly or indirectly as a result of AIDS **[Bicego et al. (2003), *Social Science and Medicine 56*: 1235–1247]**.

Table 1. Estimated Numbers of Orphans by Year and Cause, According to Region (UNAIDS, UNICEF, & USAID, 2002)

REGION	Total number of orphans by year and cause (AIDS versus all causes)					
	2001		2005		2010	
	AIDS	All Causes	AIDS	All Causes	AIDS	All Causes
Africa	11,035,000	34,294,000	16,255,000	38,915,000	20,078,000	41,994,000
Asia	1,827,000	65,504,000	3,099,000	61,563,000	4,320,000	57,220,000
L. America/ Caribbean	578,000	8,166,000	752,000	7,858,000	898,000	7,551,000
Total	13,440,000	107,964,000	20,106,000	108,336,000	25,296,000	106,765,000

Adapted from *Children on the Brink, 2002* (Available at http://www.synergyaids.com/documents/COB2002.pdf)

Despite the grim statistics, there is hope. With timely and appropriate support, affected children can still have the opportunity to live healthy and productive lives. The numbers of children affected by the epidemic are overwhelming, but effective action is possible, and a body of experience already exists in the field.

For the past two decades, nongovernmental organizations (NGOs) have been on the frontlines in the war against HIV/AIDS. Initially, NGOs focused on prevention. Today, a large number of them have taken the great leap into the arenas of counseling and testing, and mitigation, care, and support. Many of them have achieved small successes. Some have experienced challenges and frustrations in keeping pace with the epidemic. All, however, are doing amazing work, despite limited guidance tailored to their needs and realities.

During the past few years, there have been many guides, manuals, and other resources on children affected by HIV/AIDS. So, why create another document? This state-of-the-art paper attempts to consolidate information from various sources and provide NGOs with an easy reference on current thinking about children affected by HIV/AIDS. This document highlights examples from current NGO programs, and it presents them in the form of brief "Field Snapshots" and detailed case studies that describe their approaches, challenges, and lessons learned.

The final sections of this document focus on future directions for NGOs, more specifically, measuring if their interventions are effective and bringing effective interventions to scale. There are also links at the end of the document to other useful resources for more in-depth information or guidance on specific topics. Throughout the document, you will see the international AIDS logo— . This symbol is used to indicate that there are additional resources listed in Section VIII that relate to the topic being discussed in the text.

This document does not provide all the answers, but it will hopefully offer insight and guidance on ways that NGOs can fine-tune, test, or expand their efforts to improve the lives of children, families, and communities affected by HIV/AIDS.

II. Understanding the Impact of the HIV/AIDS Epidemic on Children

II.1 Who are children affected by HIV/AIDS?

Orphans are probably the most visible category of vulnerable children, but it is important to remember that there are other vulnerable children who also need support. Vulnerability due to AIDS begins long before a parent dies, and any given child may fall into different categories of vulnerability. The primary categories are orphans or any children living in households that have orphans or many children; children that are HIV-positive, heads of households, or living in households with chronically ill parents/guardians, or other family members; and children living under circumstances that place them at high risk of HIV infection (e.g., street children, displaced or abandoned children, child prostitutes, abused or neglected children, child soldiers, children living in high-conflict or war settings).

It is important to pay attention to how you refer to children affected by HIV/AIDS. "Children affected by HIV/AIDS" or "vulnerable children in AIDS-affected societies" are common terms. International experts strongly recommend that the term "AIDS orphans" not be used, since it can contribute to stigmatization or inappropriate categorization of vulnerable children. Alternative terms are "children orphaned by AIDS" or "orphans due to AIDS."

From a practical standpoint, it is hard to distinguish orphans due to different causes. All orphans have essential needs that should be met. Therefore, instead of focusing on "AIDS orphans," try to bolster support for all vulnerable children (using a community defined definition of "vulnerability") in AIDS-affected communities.

II.2 What are the needs of affected children?

HIV/AIDS is a complex issue, and while there is no single solution to preventing future infections or mitigating impact, organizations can take steps to ensure that their programs address the real needs of vulnerable children. The first step towards this goal is to have a good sense of what those needs are. Children's needs can be roughly divided into five somewhat overlapping areas of need (see Figure 1): educational, economic/material, psychosocial, safety/social protection, and health. Clearly, these needs are interrelated.

For example, economic problems can result in a household's inability to pay for school fees, which in turn often results in children not attending school. Children who are not in school might be more likely to be exploited (e.g., becoming prostitutes, soldiers, or child laborers).

NGOs have always been committed to serving the most needy and hard-to-reach members of society. Many of their initiatives have focused on health-related issues, especially ones that affect women and children under the age of 5. To effectively address HIV/AIDS in developing countries, it is important to think beyond health interventions and conventional target groups. HIV/AIDS impacts individuals, families, communities, and nations. In many societies, children and youth are severely affected by the epidemic; their lives can be seriously impacted emotionally, economically, and socially when productive members of their community die.

Figure 1. Common Needs of a Child Affected by HIV/AIDS

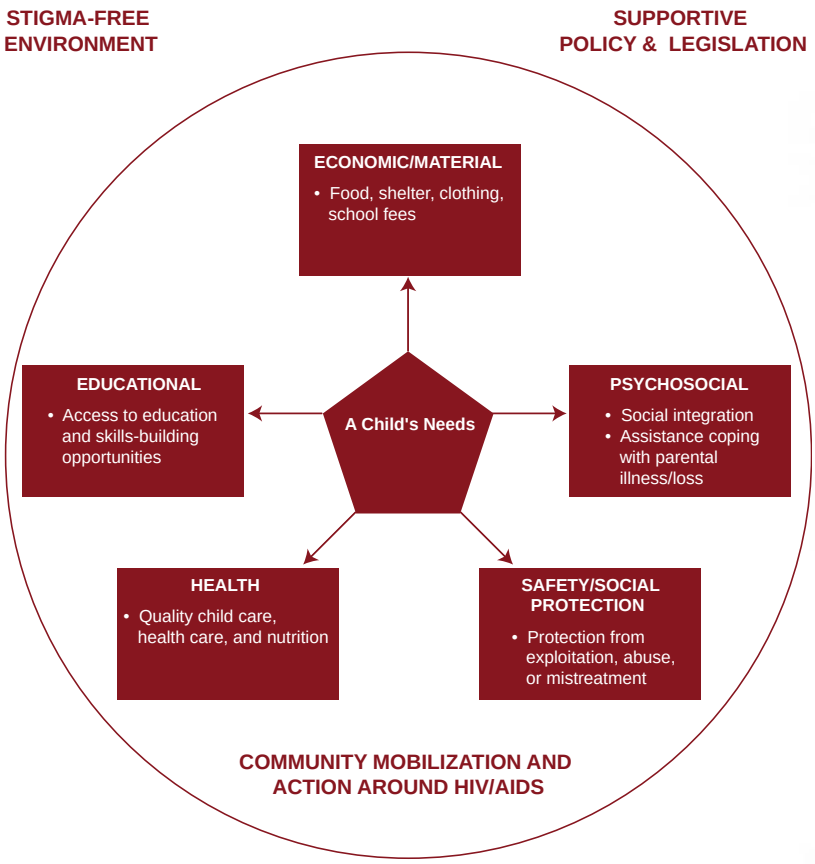


Table A (Needs and Desired Results Related to Children, and Illustrative NGO Activities) in the Appendices (Section IX.) links the needs depicted in Figure 1 with desired results and some illustrative program activities. For example, children affected by HIV/AIDS have a need to be socially integrated with their peers, adults, and their larger community. Stigma and discrimination associated with the disease often results in the social isolation of affected individuals and families, which can take a toll on a child's psychological well-being. NGOs can work with communities and other stakeholders to prevent or alleviate social isolation; for example, by organizing sports and recreation activities for all youth in the community. Creating apprenticeship opportunities for vulnerable children can help to facilitate their interaction with adults in the community as well as help them to build skills that can increase their earning potential in the future.

Some children are particularly vulnerable to exploitation and abuse. One illustrative NGO activity that could address the basic need for safety and social protection is helping communities to develop "surveillance" mechanisms to ensure timely identification and support of abused or exploited children/youth in the community. For example, an organization could train home-based care workers, social workers, teachers, and other community members to recognize the signs of abuse and establish a referral system for connecting children in need with the necessary support services. A number of NGOs have assisted community members to establish orphans registers or child protection committees, which help to identify and monitor the community's most vulnerable children.

II.3 Overview of recommended principles for programming

The previous section presented a general discussion of WHAT can be done, but it is equally important to pay attention to HOW needs are being addressed. Based on consultations with numerous stakeholders (e.g., national governments, NGOs, and youth), UNICEF, UNAIDS, and USAID developed 12 guiding principles that serve as a framework for programming. These principles, which are discussed in depth in Children on the Brink 2002, are as follows:

- Strengthen the protection and care of orphans and other vulnerable children within their extended families and communities
- Strengthen the economic coping capacities of families and communities
- Enhance the capacity of families and communities to respond to the psychosocial needs of orphans, vulnerable children, and their caregivers
- Link HIV/AIDS prevention activities, care, and support for people living with HIV/AIDS (PLHA), and efforts to support orphans and other vulnerable children
- Focus on the most vulnerable children and communities, not only those orphaned by AIDS
- Give particular attention to the roles of boys and girls, and men and women, and address gender discrimination
- Ensure the full involvement of young people as part of the solution
- Strengthen schools and ensure access to education
- Reduce stigma and discrimination
- Accelerate learning and information exchange
- Strengthen partners and partnerships at all levels and build coalitions among key stakeholders
- Ensure that external support strengthens and does not undermine community initiative and motivation.

Once needs are determined, organizations can work with communities to develop an appropriate set of interventions consistent with the principles listed above. The following section discusses specific ways that NGOs can do this.

III. Where NGOs Can Contribute Effectively

III.1 Adapting the traditional child survival model to support children affected by HIV/AIDS

In designing their child health and development activities, NGOs are most familiar with the child survival (CS) model. This model addresses important causes of child mortality such diarrhea, malaria, tetanus, and malnutrition. NGOs have used empowerment approaches to mobilize community members around key issues and facilitate community participation in developing and implementing solutions to maternal and child health (MCH) problems.

Although this empowerment approach is always encouraged, it is important to note that NGOs will need to make significant changes to the conventional CS model to develop highly effective and sustainable solutions to the problems faced by vulnerable children. The following are some key modifications:

- **Extend program activities to multiple population groups and work within existing community structures—**CS projects usually target children under the age of 5 and their biological mothers. To fully address the needs of children affected by HIV/AIDS, the reach of program activities must extend to other key target groups such as older children and youth, PLHA, guardians, foster parents, nonmaternal caregivers (e.g., grandmothers, older siblings), and heads of households (including widows and child or youth heads of households). In trying to reach the above groups, it is essential to work through existing community structures such as clan systems (by engaging traditional leaders and village heads), faith-based organizations (FBOs), farmers or peasant associations, women's groups, and community-based organizations (CBOs).

- **Expand the list of key behaviors that will be promoted—**As mentioned earlier, most CS projects promote key practices that relate to the health of mothers and children under 5. Programs supporting children and families affected by HIV/AIDS will need to promote an expanded range of behaviors that are relevant to both younger and older children/adolescents, PLHA or chronically ill individuals, and other community members (e.g., home-based care (HBC) providers, school teachers). Some of the behaviors being promoted might not necessarily be health-related. The following are illustrative behaviors that will need to be considered: nutritional management of HIV, handling of body fluids, stigma reduction, HIV sexual risk reduction, and basic financial management (e.g., among individuals who underwent micro-enterprise and development (MED) training).

- **Focus on building community capacity from the onset—**NGOs have already begun to shift from direct implementation of services to building the capacity of others to provide quality services. Programming that addresses the needs of children affected by HIV/AIDS requires an expanded commitment to capacity strengthening at different levels, with particular focus on the child, household, and community levels. It will also entail creating an environment (e.g., through national policies, laws, and programs) that is conducive to the healthy development of all children, and the well-being of the most vulnerable members of society.

- **Develop holistic and multi-sectoral responses—**HIV/AIDS is a multi-faceted problem, and it will require multi-faceted solutions. NGOs can promote collaboration between communities and different sectors, including health, education, agriculture, social welfare, religious, law enforcement, and women's affairs, as well as with the private sector (e.g., micro-finance institutions (MFIs)).

III.2 First steps in developing effective responses

Identifying Needs Collaboratively

It is important that one never make assumptions about local needs or impose external strategies on communities. Interventions will be most appropriate when NGOs collaborate with communities and other local stakeholders to a) identify needs, b) prioritize them, and c) develop solutions that are within their capacity and that will have a positive impact on children and families in the long term. Children and youth should not be mere beneficiaries of services. It is important to engage them as active participants in any processes of prioritizing, planning, and even implementing interventions.

Deciding on whom to target

There is a gut reaction to focus on orphans whose parents have died from AIDS; however, the ideal approach is to address the needs of all vulnerable children in AIDS-affected communities, not just orphans due to AIDS (especially since most people do not know which individuals within a community have HIV/AIDS). Is this feasible? Probably not—particularly in communities that are very poor (where one might find that almost all children are at-risk or vulnerable) or under circumstances when the organization is operating with very limited resources. Both of these caveats apply to the situations in which most NGOs work.

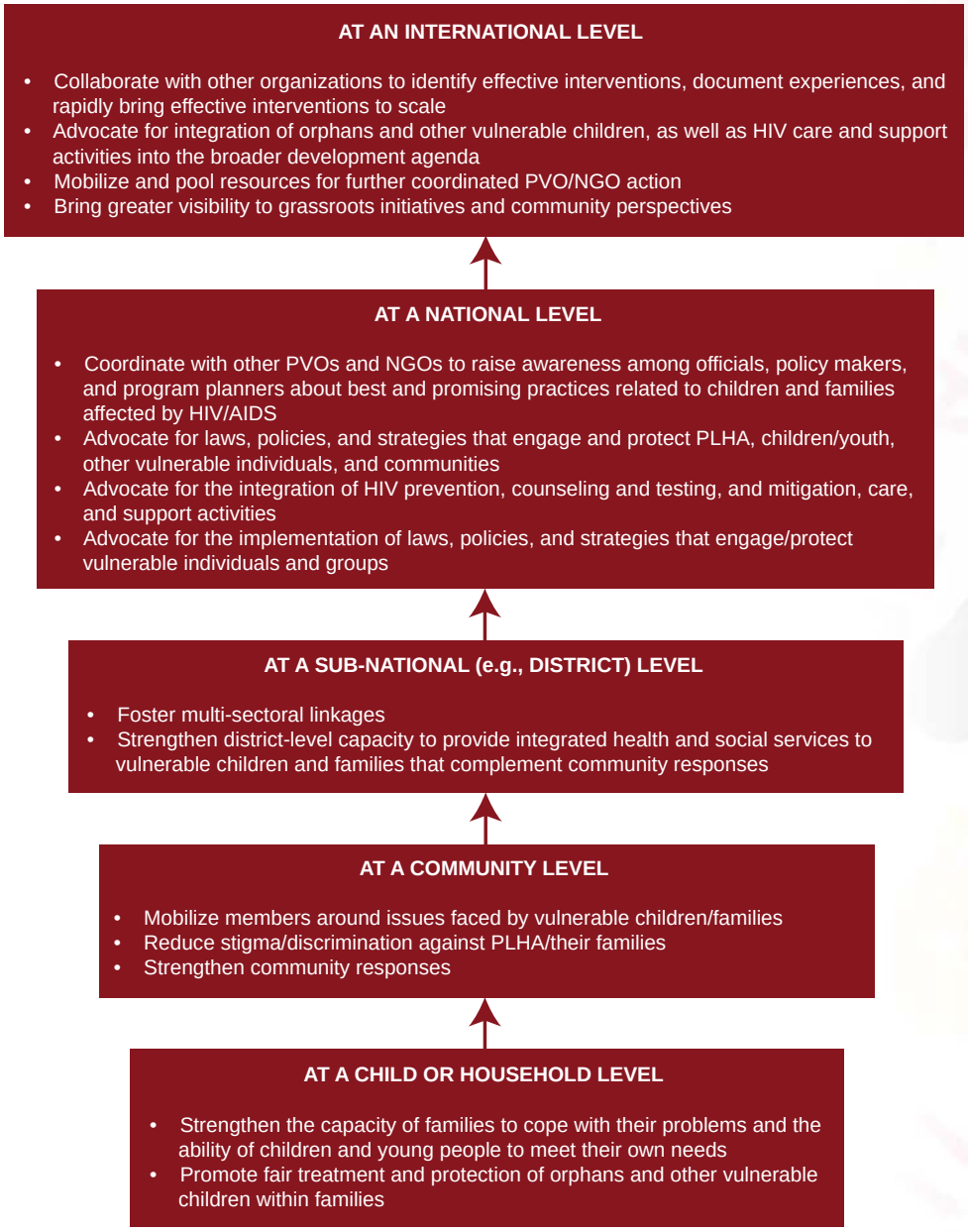
UNICEF and USAID are working on guidelines for conducting situation analyses in AIDS-affected contexts. A situation analysis not only helps all stakeholders—first and foremost, children, family, and communities—in geographic targeting, but also in prioritizing problems and gaining a better understanding of the complex dynamics underlying the situation. When all key stakeholders actively participate in the situation analysis, there is likely to be greater ownership of its findings and greater commitment to devising appropriate solutions.

Table B (Advantages and Disadvantages of Different Targeting Approaches) in the Appendices (Section IX) resents three different targeting approaches—focusing on all vulnerable children, focusing on single and double orphans, and focusing only on double orphans. It also highlights the advantages and disadvantages of each approach. As the target population is narrowed, the unfortunate consequence is that those who might need some degree of support are excluded from the focus of program interventions. However, targeting a narrower group may be necessary to effectively use the limited resources available. Attempting to meet the needs of the most vulnerable children and families may be beyond the capacity—financially and otherwise—of the community and facilitating organizations. An important part of targeting is helping communities to come up with their own criteria for determining who is "most vulnerable" in the context where the intervention takes place. This is highly advisable rather than imposing set definitions determined by external agents, who often make assumptions about who is vulnerable.

Determining areas of action

Although NGOs are historically known for their accomplishments at the grassroots level, there are many different options in terms of NGO action. The framework depicted in Figure 2 builds on the 12 guiding principles that were summarized in Section II.3. It indicates the levels at which an implementing organization might operate to create an enabling environment that supports vulnerable children. The next section presents the promising practices at each level of the framework.

Figure 2. Framework for NGO Action to Support Children Affected by HIV/AIDS



IV. Taking Action

Previous sections of this paper discussed guiding principles and key considerations when attending to the needs of children affected by HIV/AIDS, but how can organizations translate them into effective actions and, ultimately, results? There is an overwhelming number of examples of NGO action at the grassroots level. As a result, a substantial portion of this section emphasizes action at the child/household, community, and to a lesser degree, sub-national (e.g., district) levels. It discusses promising practices at each of those levels and presents NGO illustrations. In light of the potential for NGOs to contribute at other levels, this section also highlights ways in which NGOs can make contributions at the national and international levels. This section also offers short "field snapshots" of innovative and/or effective ways that NGOs are addressing the needs of children and families affected by HIV/AIDS.

Promising Practices at the Child/Household Level

- **Use memory books and other tools that help PLHA and their children to express their thoughts, feelings, and fears related to the illness and death**
- **Assist PLHA with succession planning**
- **Promote adequate and equal treatment of orphans within families by targeting nonmaternal caregivers and/or household decisionmakers**
- **Promote backyard gardens to produce nutritious foods for PLHA and their families**
- **Develop HIV/STI and pregnancy prevention strategies and messages targeting vulnerable youth**
- **Provide vulnerable individuals and families (e.g., widows, youth affected by HIV/AIDS, child- or youth-headed households, households with orphans or chronically ill members) with access to credit or MED training and support**
- **Offer vocational training, apprenticeships, or other forms of skills-building for vulnerable youth**
- **Integrate services for orphans and other vulnerable children with home-based care (HBC) in order to identify and link children in AIDS-affected households with essential support (e.g., psychosocial services, education, health care, material support) *before* they become orphans**
- **Provide outreach services (e.g., health care, HIV prevention, re-entry into school; income-generation) to street children and out-of-school youth**

Many NGO activities address more than one need; a given activity, for instance, may have a positive effect on the psychological, educational, and health status of a child. As a result, the section is organized according to level of action, rather than the type of need that is being addressed.

IV.1 Child/household level

NGOs frequently take action at the grassroots level, aiming to strengthen the capacity of families to meet their children's needs, and to increase the capacity of children and young people to meet their own needs.

Children with HIV have special needs, such as coming to terms with the illness, managing the illness, and preparing for the future. There are a number of promising NGO practices at the child or household level. For example, PLHA, orphans, and other vulnerable families (e.g., widows and youth-headed households) can benefit from credit or MED training as a means of generating additional income. For an illustration of this approach, see the "Helping Others Help Themselves" (World Vision South Africa's MED Project) case study in Section V. To meet the educational needs of vulnerable children, programs can offer vocational training, apprenticeships, or other forms of skills building for youth. Some programs may implement activities that focus solely on the education of children, while others may include educational outreach services for at-risk children and youth as a critical addition to traditional HIV-prevention strategies.

Four promising practices have surfaced focusing on the health and nutrition needs of vulnerable children and youth. These practices include the following:

- Promoting backyard gardens to produce nutritious foods for PLHA and their families
- Integrating orphan care with HBC to identify and link children in AIDS-affected households with essential support (e.g., psychosocial services, education, health care, material support) before they become orphans
- Developing HIV/STI and pregnancy prevention strategies and messages targeting vulnerable youth
- Providing outreach services (e.g., health care, HIV prevention, re-entry into school, income-generation) to street children and out-of-school youth.

An increasing number of NGOs are paying attention to the psychological needs of vulnerable children. One way to do this is as a part of succession planning. Succession planning is when parents living with the disease put together a plan for their child/children's care after they have died. Such planning is essential so that the support of orphans can be established and the child/children are better prepared once their parents have died. Assisting PLHA with succession planning not only helps to secure their children's future, it can be an opportunity to promote coping between parent and child. One activity that addresses psychosocial (among other) issues is the introduction of memory books and other tools to PLHA and their children (see sidebar).

Others projects have trained volunteers or social workers to provide psychosocial services to affected children and families. Regardless of the specific approach that is taken, there are major issues to consider. For example, the International HIV/AIDS Alliance's Building Blocks publication on psychosocial support highlights the effects of various stresses (such as losing a parent or being discriminated against) on OVC. Effects include anxiety, low self-esteem, guilt, anger, aggressiveness, drug/alcohol abuse, and social withdrawal. The following snapshot shows how Christian Children's Fund (CCF) is addressing the psychosocial needs of people affected by HIV/AIDS in Uganda.

What Is a Memory Book?

In many of the societies affected by HIV/AIDS, it is taboo to talk about death. Memory books can be an effective way of helping families sort through difficult circumstances and an uncertain future. A memory book does not necessarily have to be a book. It could be a box, a basket, or just a bundle of items. The process of creating a memory book is as valuable as the end product. An HIV+ parent and his or her children can create a memory book together, and the process helps them express their thoughts, feelings, and experiences through words or pictures. Memory books can contain drawings, photographs, information on the family history, and stories about the parent and child.

PVOs and NGOs can support PLHA and their children in creating memory books as a part of their home-based care activities, HIV post-test clubs, or other care and support activities.

For two examples of how PVOs are using memory books, visit the following links:

http://www.childreach.org/docs/uganda.pdf

http://www.ifrc.org/docs/news/02/02112001/

Field Snapshot 1. Psychosocial Support

For more than two years, CCF has piloted a psychosocial program for children and families affected by HIV/AIDS in Uganda. The program trained social workers to be psychosocial workers (PSWs) and involves one-on-one interaction between trained PSWs and affected children outside of the home setting, home visitation to help affected children and family members better cope with emerging issues, school-based activities to reduce stigma related to HIV/AIDS, and group activities such as games and artwork that allow affected children to express their feelings.

CCF is also developing a how-to manual on simple yet effective activities such as creating memory books or picture drawing and other forms of emotional expression with step-by-step instructions on facilitating various psychosocial activities.

CCF has also worked with Pathfinder International-Uganda to develop a PSW training curriculum. The training lasts 4 months and covers everything from theoretical perspectives on child counseling to specific skill sets and activities in dealing with inappropriate/self-destructive behavior or other psychosocial issues. For more information, contact CCF at: 2821 Emerywood Parkway, Richmond, VA 23294; Tel: (804) 756-2700 or visit their Web site at www.christianchildrensfund.org.

Safety/social protection activities at the child/household level that can help ensure that OVC are not mistreated or abused include efforts such as assisting PLHA with succession planning and targeting nonmaternal caregivers with specific activities or behavior change messages to reduce the likelihood of differential treatment of orphans. In AIDS-affected communities, it is particularly important to engage all individuals who are responsible for caring for children. Quite often, it is the grandmother, an older sibling, or another relative who becomes the primary caregiver once a child's parents die. In many contexts, orphans and other children who are cared for by nonmaternal caregivers tend to be more at risk for illness and malnutrition compared to children who are cared for by their biological mothers. NGOs are beginning to work more closely with nonmaternal caregivers. Field Snapshot 2 highlights one NGO's efforts.

Field Snapshot 2. Targeting Nonmaternal Caregivers

Medical Care Development International's (MCDI) CS project in KwaZulu Natal, South Africa has observed that children who have nonmaternal caregivers are at a major health disadvantage (e.g., lower immunization coverage, lower rates of health care-seeking for common illnesses) than children whose primary caregiver is the biological mother. As a result, the project has developed special strategies that target nonmaternal caregivers (which in the local context, tend to be grandmothers (a.k.a., grannies)). The project takes advantage of golden opportunities to promote positive behaviors in this group, for example, at pension-collection gatherings or at churches.

For more information, contact MCDI at: 8401 Colesville Rd., Silver Spring, MD 20910; Tel: (301) 562-1920; fax: (301) 562-1921; or e-mail them at mcdi@mcd.org.

To support the work being done at the child/household level, certain elements need to be in place at the national level. For instance, institutions that administer care to children (e.g., orphanages and other child-care institutions), as well as the placement of children in foster care, should be carefully regulated. In some countries, NGOs have been instrumental in promoting the establishment of National Orphan Care Task Forces. Even in the absence of a formal body that address the needs of orphans and other vulnerable children, NGOs can play a critical role in communicating the needs of vulnerable children to governments and external organizations, raising issues of gender and social equity and promoting the establishment and implementation of supportive national laws, policies, and programs.

IV.2 Community level

While efforts at the child/household level work to strengthen the abilities of children and families, the aim of NGO activities at the community level is to stimulate and strengthen community-based responses, helping communities to define needs, identify vulnerable children and households, and respond in a timely and effective manner. Organizations are searching for sustainable ways to work in partnership with communities to mitigate the effects of the epidemic. As the long term goal of a NGO is to promote sustainability and community ownership of an initiative, there are two overarching principles: to strengthen the community's capacity to cope with this crisis (at present and in the long term) and to take their actions to scale. The following is a description of the practices that have been useful in addressing vulnerable children's needs at the community level.

One practice that has been effective in focusing on the economic/material needs of vulnerable children is organizing community members to provide material support (e.g., food, clothing, school fees). The educational needs of working or street children can be addressed by establishing alternatives to formal schooling (e.g., community schools that have flexible hours of operation (e.g., in the evening or on weekends)). Two key promising practices have emerged regarding the health and nutritional needs of children and families: creating community gardens to improve access to food, and establishing and strengthening a home-based care network to address the health care needs of vulnerable families.

Other promising practices at the community level focus on the psychological and safety/social protection needs of vulnerable children. Community-based childcare (see Field Snapshot on MCDI's model crèche program) and sports and recreation activities for children and youth are two programs that encourage social integration with the larger community and youth-to-youth support. These activities can help to reduce the stigma associated with the disease and invoke compassionate community-based responses.

Promising Practices at the Community Level

- **Work with communities to establish alternatives to formal schooling (tailored to meet the needs of working or street children)**
- **Community gardening**
- **Establish/strengthen a HBC network that addresses the needs of both PLHA and their children**
- **Organize community members to provide material support (e.g., food, clothing, school fees) to vulnerable children/ households**
- **Reduce stigma directed at PLHA and their families through SBC activities, and invoke compassionate community-based responses to the needs of children and families affected by HIV/AIDS**
- **Engage traditional and community leaders to enforce social protection of widows, orphans, and other vulnerable members of society (e.g., inheritance issues, property retention)**
- **Use SBC strategies to address social norms, myths, and/or practices that place children at risk of getting HIV or being physically or sexually abuse/exploited**
- **Link programs that support orphans and other vulnerable children with programs that address abuse, mistreatment, or exploitation of children (girls, in particular)**
- **Engage adults in the community to provide care, protection, mentorship or other positive social/emotional adult-child connections with orphans and other vulnerable children (e.g. through home visits)**
- **Introduce community-based childcare as a way of integrating children affected by HIV/AIDS with the larger community**
- **Establish sports and recreation activities to provide youth-to-youth support and social interaction.**

Field Snapshot 3. Community-based Child Care

MCDI South Africa started a model *creche* (a day nursery for underprivileged children) for orphans who have been identified by the community as being the most needy. The rationale for establishing this community-based child care is two-fold: 1) it provides vulnerable children with care by teachers who are trained in early child care and have been sensitized to the special needs of children affected by HIV/AIDS, and 2) it enables orphans to interact socially with other children from the community. Orphans attend the *creche* free of cost (costs are covered using fees paid by the parents of other children who attend the *creche*).

The *creche* program has helped to reduce stigma and discrimination directed at children affected by HIV/AIDS. MCDI is also partnering with a faith-based organization, Ekhaya, to provide additional services such as food parcels and toys to the *creche*, as well as seeds and fertilizers for household gardening to vulnerable families.

For more information, contact MCDI at mcdi@mcd.org.

At the community level, the safety/social protections needs of vulnerable children can be addressed by engaging traditional and community leaders to enforce laws protecting widows, orphans, and other vulnerable members of the community (e.g., inheritance issues, property retention), facilitating connections with police and law enforcement, and by linking programs with other services that address abuse, mistreatment, or exploitation of children (girls, in particular). NGOs have also been instrumental in facilitating the establishment of orphan/vulnerable child surveillance systems. The following snapshot illustrates work undertaken in Zimbabwe to strengthen social protection of OVC.

Field Snapshot 4. Identifying and Linking the Vulnerable with Services

Family AIDS Caring Trust (FACT), an NGO in Zimbabwe, used a participatory approach to identify and track orphans in the community. Project volunteers worked with village heads and councilors to enumerate orphans in the community and identify those in greatest need. The community was responsible for defining "need" (vulnerability). All orphans were recorded in a Priority Register and were eligible for bi-weekly household visits. During these household visits, volunteers determine needs via observation, as well as direct inquiry of the orphan(s).

A further dimension of their surveillance system was developed in 1998, when a psychologist working as a volunteer for FACT/Zimbabwe trained volunteers in identification and management of abuse cases. Having such a group in the community allows for the detecting and reporting of existing cases and reducing the instances of abuse in the future.

For more information, contact FACT at: 52 Robertson St., Masvingo, Masvingo, Zimbabwe; Tel and fax: 263-(0)39-65677; or e-mail them at factnet@mweb.co.zw.

NGOs should tap into their vast experience facilitating social and behavior change, and they are encouraged to develop strategies to address social norms, myths, and/or practices that place children at risk of getting HIV or being physically or sexually abused or exploited.

Field Snapshot 5. Social Integration of Youth Affected by HIV/AIDS

The Community-based Options for Protection and Empowerment (COPE) project (Save the Children-USA) in Mangochi District, Malawi was instrumental in supporting the establishment of Village AIDS Committees (VACs) and Community AIDS Committees (CACs). Project staff worked closely with village leaders and other stakeholders to conduct needs assessments and establish activities such as the following:

- **Identification, monitoring, assistance, and protection of vulnerable children—**An enumeration process of determining vulnerable children using the clan head system—a traditional way of monitoring needs in the community was conducted. VAC members paid house visits to the orphans and offered material support such as clothing, maize, rice, and soap.
- **Community fundraising—**Examples of such projects are video shows, community gardens, and working in farmer's plots for cash. Individual CAC and VAC members also made contributions to their committee's fund.
- **Training—**COPE trained CAC members who in turn trained village-based trainers. The village-based trainers trained caregivers. Besides training community members, COPE also conducted institution-based training to strengthen linkages between health care providers.
- **Youth club formation—**This activity was suggested by the community. These clubs were instrumental in promoting messages on HIV/AIDS prevention, as well as promoting child-to-child support.
- **Structured recreation activities—**These activities were designed specifically to address psychosocial needs. Through organized play and other creative activities, their purpose was to diminish marginalization and stigmatization of orphans.
- **Wetland gardens assistance—**Beneficiaries of this activity (e.g., guardians of orphans) were identified by the VAC. The Ministry of Agriculture was closely involved in monitoring and support of these gardens.

As with work that is done at the child or household level, it is important to have supporting government policies/legislation that address the health and social problems of children, youth, and other vulnerable groups. NGOs can play a vital role in promoting these elements through national-level advocacy.

IV.3 Sub-national/district level

Activities at the child, household, and community levels tend to concentrate on the direct needs of children and families. In contrast, NGO action at the sub-national (e.g., district) level has focused on interfacing communities with government or private-sector structures, and building public-sector capacity (by working with different sectors) to support vulnerable children and families through the provision of essential services.

Some NGOs have worked with the education sector to integrate life-skills training into school curricula. Others have trained teachers and youth in school-based HIV prevention, or supported the establishment of anti-AIDS clubs. PVOs have also worked with the health sector on the following: 1) ensuring that the services intended for youth are indeed "youth-friendly" (see sidebar), 2) increasing access to HIV counseling and testing services, 3) strengthening linkages between counseling and testing and care and support, and 4) promoting links between schools and health clinics that provide services to children and adolescents. Strengthening mechanisms to reach out-of-school youth with essential services (e.g., health care, education, income-generation, psychosocial support) will cut across the health, education, economic, and psychological needs.

Quite often, service providers are major contributors to stigma and discrimination toward children and families affected by HIV/AIDS. NGOs can work with different sectors to address fears, attitudes, and/or practices among service providers and teachers.

Promising Practices at the Sub-national Level

- **Work with the health sector to establish youth-friendly clinics**
- **Promote links between schools and health clinics that provide services to children and adolescents**
- **Train teachers and youth (as peer educators) in school-based HIV prevention**
- **Address fears, attitudes, and/or practices among service providers**
- **Increase availability of and access to HIV counseling and testing services**
- **Strengthen linkages between counseling and testing and care and support**
- **Provide life-skills training to vulnerable youth**
- **Strengthen mechanisms to reach out-of-school youth with essential services (e.g., health care, education, income-generation, psychosocial support)**

What Makes a Service Youth-friendly?

The following are some characteristics to keep in mind when evaluating if services are youth-friendly:

- **Convenient hours or locations for youth**
- **Friendly and nonjudgmental staff**
- **Respect for youth's desires for privacy**
- **Outreach to youth who cannot reach clinics (or are too embarrassed to be seen at clinics)**
- **Youth involvement in designing and providing services.**

IV.4 National and international levels

Although NGOs tend to work at the grassroots level, they can also bring their experience and contacts at the community level to national and international arenas. They can advocate for integration of orphans and vulnerable children and HIV/AIDS care and support activities into the broader development agenda, and provide a voice for grassroots initiatives and individuals, families, and communities affected by HIV/AIDS.

Advocacy is a critical activity. The following are important questions to consider when advocating for children affected by HIV/AIDS:

- Does the country have a strategic plan and budget for HIV/AIDS?
- Does the country have a comprehensive national AIDS program that links prevention, voluntary counseling and testing (VCT), treatment, care, and support?

- Are there government policies/legislation that address the health and social problems of youth?
- Are there child protection laws that address issues such as child labor, physical or sexual abuse, child prostitution, street children?
- Is there a national policy for protecting the rights of widows/orphans to retain land or other property of deceased individuals?
- If there are institutions that administer care to children (e.g., orphanages), are they well regulated?
- Is there gender equity in terms of access to high-quality education and health care?
- Are there human rights policies protecting vulnerable members of society (e.g., women, ethnic minorities, refugees, migrants, commercial sex workers, interjecting drug users (IDUs), homosexuals, etc.)?
- Does the country have a National Task Force on orphans and other children affected by HIV/AIDS?
- Is foster placement of children regulated?
- Are there laws, policies, or strategies that protect the rights of women and girls?

Partnering with other organizations to raise awareness among policymakers and bring vulnerable individuals and communities to the fore is a viable option. The Hope for African Children's Initiative case study in Section V describes how a group of PVOs joined together to coordinate and collaborate to mobilize the international community around the issues faced by children in Africa. Creating in-country and multi-country networks to share experiences and disseminate innovations is also vital to highlighting issues of quality, effectiveness, and impact, as well as taking action to scale. Many PVOs are also promoting intra-organizational standardization (when appropriate), maximizing the use of limited resources, and creating mechanism for rapid diffusion of information and innovations through their own multi-national initiatives.

Section V presents four case studies that illustrate some of the issues and practices and demonstrate how organizations can implement effective programs at various levels (child/household, community, etc.) and focus on various needs (education, psychological, etc.).

V. Case Studies of NGO Programs

This section details four case studies of different organization's efforts to make a positive impact on children affected by HIV/AIDS. The first case study from the Ark Foundation of Africa (AFA) provides services to vulnerable youth, 85 percent of whom are orphans due to AIDS. AFA has not only addressed the children's needs for food, shelter, and clothing, but they also tackle important issues such as preserving a child's identity after his/her parents have died. These youth are then charged with mentoring young children who are also vulnerable to the effects of AIDS.

Case Study 1. Reaching Out and Reaching Back: The Ark Foundation's "One-Stop Center"

Many public health programs emphasize the physical well being of children under the age of 5. Indeed, the first 5 years are a critical period of a child's life, but in dealing with children affected by HIV/AIDS, it is essential to acknowledge that vulnerability extends far beyond the first 5 years of life. It is also important to realize that children's needs are not limited to shelter, food, and clothing.

AFA (http://www.arkafrica.org/) provides an example of how NGOs are responding to the multidimensional needs of vulnerable children. Through its "One-Stop Center" in Dar es Salaam, Tanzania, AFA is reaching out to vulnerable inner-city youth aged 13–20 years and providing a forum for these older youth to reach back and mentor younger vulnerable children.

AFA's Approach

AFA started the "One-Stop Center" in 2001 as a comprehensive approach to fighting HIV, illiteracy, joblessness, and poverty among youth. The center serves 235 orphans and vulnerable children aged 13–20 years. At least 85 percent of those children are orphans due to AIDS. The program takes the following four-tiered approach: 1) educational development, 2) vocational training, 3) spiritual development, and 4) social development. Major program services include the following:

- Food, transportation, and recreational activities
- Health education (including HIV prevention, counseling, and referrals for HIV testing)
- Basic life skills training and skills building in parenting and household management
- Job training and placement
- HIV peer educator training
- Working with school officials to enable orphans and vulnerable children to re-enter the formal school system
- Providing formal secondary school system (curriculum)
- Emergency assistance for housing, burial, school fees, and basic medication such as aspirin. Doctor's visits are also paid for, as needed.

In many African societies, culture is deeply rooted in oral tradition. Parents and elders play a vital role in passing on information related to history, culture, and heritage. When a child's parents die, conscious efforts must be made to preserve the child's sense of identity. AFA observed that orphans in its program yearned for a sense of belonging. The One-Stop Center infuses culture and African history throughout its program activities. It also facilitates mentoring relationships between older and younger orphans, as well as between program "graduates" and current beneficiaries. The center takes in children many of whom have been out of the school system for years; the center's one-on-one helps individual children with individual needs to catch up with other students.

It is noteworthy that the program also consulted the youth on ways to build group solidarity and create a sense of identity. The children designed a student identification (ID) card with their name, photo, and what grade they are in. The major purpose of the ID is to receive a discount on public transportation back and forth from the center to home and of course in case of an accident. The ID does not show any information about HIV status or any other personal information.

In addition to addressing psychosocial, cultural, and educational needs, the One-Stop Center aims to meet some of the material needs of its beneficiaries. Initially, youth were offered meals at the Center; however, many youth would not accept the meals because their relatives did not have access to food. A major lesson learned out of this experience is that entire families must be regarded as beneficiaries, not just the child. Today, each child that needs it takes dry goods home to his/her family at the end of the week.

Children attend classes as well as work at the center. There are two sessions of classes, morning and afternoon; therefore, the children who attend classes in the morning can work in the afternoon and those who attend classes in the afternoon can work in the morning. The children fill all nonprofessional positions at the center, such as working at the front desk-reception or operating the VitaCow (a machine used in soy milk production). Children working at the center receive a $10 monthly stipend. This approach has enabled program benefits to extend far beyond the individual child.

Preserving the Past, Securing the Future

In addition to meeting the immediate needs of vulnerable children, the One-Stop Center aims to improve their futures. Upon the death of their parents, many youth are no longer able to attend school. The Center

provides opportunities for the youth to continue their formal education. The program has also formed partnerships with local universities and the private sector-an advantage of operating in an urban setting. University students serve as interns with the program, (e.g., as teachers or counselors) and older program beneficiaries pursue internships at local businesses. Through this mechanism, the Center also provides opportunities for vocational skills building in areas such as custom services, carpentry, art, or dressmaking.

The One-Stop Center uses measures such as the rate of employment among program graduates and the high-school entrance exam pass rate among its beneficiaries as indicators of success. To meet the multidimensional needs of its beneficiaries, the Center spends the equivalent of US$11 per month per child. This value includes transport, meals, academics, vocational training, and staff salaries. About 95 of former participants have received decent paying jobs, and others have been accepted in area universities, teachers colleges, and other institutions. Some have been hired as part of the full-time paid staff at the center.

AFA has an interesting funding structure that includes international grants, in-kind donations, and income-generation activities. The organization received a grant from the A.C. NAVA Charitable Foundation (a faith-based trust that funds activities in both the United States and abroad), which provides funding for several years, and AFA has received additional funding from the Global Fund for Children and Child Mission from Brazil for the next 3 years. The Center has also benefited from in-kind contributions. For example, the America Soybean Association donated a "soya cow," which enables the project to produce soymilk and other soy products. Fifty percent of what the Center produces is used to meet the dietary needs of the children and their families, while the other 50 percent is sold for profit in Dar Es Salaam. The program produces approximately 250 liters of soymilk each day, in addition to tofu, yogurt, and milk shakes. Any surplus is used for snacks for the children to eat, but the children also sell some of the soy products in Dar es Salaam. Today, the center is 45 percent self-sustaining.

To scale up, the center has developed a peer-to-peer program in which PEP/International, a U.S.-based program, has trained 75 teens. Additionally, former graduates provide counseling and support to current program beneficiaries.

Challenges

The greatest challenge faced by the One-Stop Center has been keeping pace with the HIV/AIDS epidemic. Social workers, churches, NGOs, and private providers continue to refer orphans and vulnerable children to the program. However, AFA has limited resources to bring this promising program to scale. The Government of Tanzania is impressed with what the program has accomplished, and it has donated land to expand the program's operations. However, AFA has had difficulties securing resources for building materials. Another challenge in going to scale will be personnel. At present, the One-Stop Center has been able to provide the children with one-on-one counseling by its staff. Most NGOs will not have this luxury. As the program expands, there will be a need to further explore alternatives such as peer counseling and support and the mentoring of program beneficiaries by program graduates. There is also tremendous potential to tap into financial and human resources that exist within the private sector.

Summary of Lessons Learned

- When a child's parents die, conscious efforts must be made to preserve the child's sense of identity. Consult children on ways to build solidarity as a group and maintain their cultural and personal identities. Such a program should allow siblings who live in separate homes to have a place to meet and stay together at least during the day so they can maintain a connection with each other.
- To maximize outcomes among children affected by HIV/AIDS, entire families (and sometimes communities) must be regarded as beneficiaries, not just the individual child.

- The children must be equal partners in the process from beginning to end.
- A diversified funding structure is important to sustaining (and ultimately, expanding) program activities. Explore in-kind donations from the private sector that can be used to both generate income for the program and meet immediate needs of program beneficiaries.

To learn more about the One-Stop Center, contact Ms. Rhoi Wangila, Executive Director of AFA, at rkaima@hotmail.com. AFA's headquarters may also be contacted at: 1505 N. Capitol St., NE, Washington, DC 20001; Tel: (202) 832-5420, Fax: (202) 829-5596.

Case Study 2. Helping Others Help Themselves: World Vision South Africa's Intersectoral HIV/AIDS Micro-enterprise Development Project

While the AFA in the previous case study concentrates on the needs of children, World Vision, highlighted in the next case study, focuses on building the economic capacity of families in order to prevent infection, receive quality care if infected, and better cope when a family member is infected. The case study identifies the challenges they have faced, as well as the many lesson learned during the 4 years of the MED project in KwaZulu, South Africa.

One cannot underestimate the role that poverty plays in fueling the HIV/AIDS pandemic. It motivates young women to engage in risky sexual behavior for economic gain. It is linked to an individual's access to quality health care and education. And it affects a household's ability to cope when a family member is diagnosed with HIV.

An Intersectoral Approach to Mitigation

For the past 8 years, World Vision has been implementing the Thukela District Child Survival Project (TDCSP) in KwaZulu Natal, South Africa-a region where the estimated antenatal HIV seroprevalence rate is 34 percent. In places where HIV/AIDS has such a strong hold, it is impossible to ignore the negative impact of the epidemic on children, families, and communities. In December 1999, World Vision and its local partners started an intersectoral HIV/AIDS MED intervention. The intervention, which is being funded by USAID/South Africa as an add-on component to the TDCSP, aims to strengthen the ability of vulnerable individuals and households to withstand the negative impacts of HIV/AIDS.

Program activities target both individual orphans, as well as households with orphans and chronically ill family members. Home-based care volunteers, community members, and even orphans identify other orphans in the community, and an overall register for the pilot projects is kept by the orphans project manager. Very young orphans are encouraged to participate in program activities, along with their caretakers, some of whom are part of the community orphan committee in their area. The TDCSP plans to address the specific needs of young orphans more directly during the next phase of the project.

The HIV MED team works closely with other agencies and institutions to ensure that a holistic approach to HIV/AIDS mitigation, care, and support is taken. This includes the following:

- Micro-enterprise training for vulnerable households, women, and youth
- Establishing a HBC network
- Improving community capacity to support orphans.

To determine who would be considered vulnerable, the community determined that orphans up to age 25 years should be included, instead of the original project plan to target orphans 18 years and younger. In some instances, such as with negotiating school fee waivers, orphans themselves determine who is eligible. It is clear, however, that the definition of vulnerability is fluid and will shift over time. The MED training

is aimed at project areas where there is a higher percentage of ill people and orphans. Those interested in the MED training are then screened; those with demonstrable entrepreneurial orientation are selected to attend the training.

There has also been some preliminary work to develop labor-saving technologies. World Vision is making an earnest effort to strengthen linkages between intervention components, and its project staff work closely with a number of sectors (e.g., Departments of Health, Social Development, Home Affairs, and Agriculture) in Thukela.

The following are some of the objectives related to the TDCSP's intersectoral MED activities:

- To maintain or improve incomes of households with acutely/chronically ill family members (those who have been bedridden for 5 days or more during the last 2 weeks; the project does not distinguish between illness due to HIV/AIDS or other causes -or- households that have taken in orphans through MED activities). HBC volunteers and community health workers (CHWs) have been important in identifying these households.
- To increase women's and youth's ability to provide financially for their households and decrease risk behavior, through their involvement in MED-linked activities.
- To increase awareness of and response to the HIV/AIDS pandemic among civil society, local institutions/groups, and intervention target groups through activities such as labor saving, collaboration, and networking within the community.
- To increase knowledge, skills, and support of households with acutely or chronically ill family members to care for the chronically ill.
- To increase awareness and knowledge of households and communities with orphans to appropriately care for the orphans.

More Money Leads to Better Mitigation?

World Vision trained 100 community members to be HBC volunteers. They have been well received within the community and have helped to reduce the burden placed on hospitals to provide care and support services.

To date, 400 hundred people have received MED training, either by World Vision or by one of its partner organizations, such as Okahlamba Area Development Programme. Nine out of every 10 individuals trained by World Vision are operating successful businesses (average US$50 per month). However, the big question is, "Are vulnerable individuals and families better off as a result of the intersectoral MED intervention?" Answering that question requires a clear vision of what the intervention is aiming to achieve, as well as time, trained personnel, and resources for follow up. To this end, the next steps for the TDCSP project are to define terms such as "better off" and "well-being," and to begin the process of developing indicators.

The project has undertaken a number of data collection activities (to aid in targeting services and assess changes in key health, social, economic, etc. outcomes), although they are mostly limited to baseline and/or final assessments. The following are examples:

- Rapid household scan at baseline (to identify households with ill members or orphans, and to aid in targeting interventions and resources)
- Household economic survey among vulnerable households (to gather information on demographics, migration, access to various services and facilities, livelihood strategies, food spending and consumption, and ownership of physical and financial assets)
- Assessment of how people have used the money they generated in their businesses (such as reinvested into their business, used for family or personal needs, or given to other family members)

- Sexual risk behavior survey among MED trainees
- Orphan survey (to collect information on school attendance, physical needs, access to grants, household needs)
- Survey and baseline assessment with questions about positive living, reasons to get tested, HBC issues (caring for an HIV positive person safely at home, issues around stigma, etc.), and orphan issues (terminally ill parents making wills and appointing guardians)
- HBC evaluation to determine what care is being offered to patients in the system.

A further development is the piloting of a "Wellbeing Card" for clients to carry to facilitate communication and referrals among the various people involved in the holistic wellbeing of clients. A major challenge has been determining whether the micro-enterprise intervention is improving the ability of vulnerable individuals and families to cope with the negative impacts of HIV/AIDS.

As a reminder, in situations where activities are being piloted, operations research can be used to test entire intervention packages or intervention components (e.g., comparing key outcomes/ results between communities where MED activities are being implemented and where they are not being implemented). This approach may be more beneficial than initially doing research, and then designing an intervention using the results of that research; as TDSCP has seen, the community receives an immediate benefit, and it is much easier for the participating organization to co-design the package with the community.

The TDCSP underwent its midterm evaluation in 2001. The evaluation highlighted some challenges faced by the intersectoral MED program. The following are some examples:

- Developing indicators of well-being
- Engaging older orphans
- Creating strong linkages between the different project components
- Addressing issues related to volunteerism (e.g., incentives for home-based care workers)
- "Movement" of beneficiaries between the different categories of need (no chronically ill member, chronically ill member, orphans present). (World Vision has developed a database to track status of MED trainees.)

Summary of Lessons Learned

- Clear mechanisms for linking different HIV/AIDS-related services facilitates timely identification of vulnerable individuals and families, and is conducive to holistic approaches to mitigation, care, and support of HIV/AIDS-affected individuals, families, and communities.
- Poverty is a root cause of many problems, and it is difficult to isolate the degree to which changing household economics affect key HIV/AIDS-related outcomes. Before initiating a MED intervention, it is important to have a clear idea of how effectiveness and/or impact will be measured using a mix of qualitative and quantitative methods. Project evaluators must take into account any issues that will complicate tracking economic changes, such as the effects of seasonality. It is also important to identify intermediate results, not just outputs (e.g., number of people who underwent MED trained) that can be tracked throughout the life of the program, not just when the project ends.
- HIV/AIDS is a dynamic problem, and more often than not, there will be "moving targets." Classifying individuals and households (e.g., households with orphans versus a chronically ill member) is helpful for targeting purposes. However, as the project progresses, it is not always feasible, and perhaps not as important, to keep beneficiaries confined to rigid categories of need. It is useful, however, to systematically track changes in status.

For more information about the above activities, contact Monika Holst (monika_holst@wvi.org), Project Manager for TDCSP. General contact information for TDCSP is at: P.O. Box 37, Bergville 3350, KwaZulu Natal.

Case Study 3. Meeting Needs through Ministry: World Relief's Role in Empowering Churches to Develop Sustainable Responses

The next case study details the ways in which World Relief has mobilized communities around families and children affected by HIV/AIDS. Unlike AFA and World Vision in the earlier case studies, World Relief does not provide direct services to children and families through its ministry project in Malawi; their program has harnessed the commitment to service held by churches and church congregations by facilitating the implementation of sustainable solutions generated by church members. The results have been sustainable and holistic activities at the community level.

NGOs are always looking for approaches that are both effective and sustainable. World Relief (http://www.wr.org) believes that the biblical mandate given to Christians to serve the needs of the poor and those marginalized from the rest of society is a powerful model for how Christians should respond to the needs of PLHAs and/or children and families affected by HIV/AIDS.

In two districts in northern Malawi, World Relief is equipping local churches with the information and skills to provide mitigation, care, and support services to children and families affected by HIV/AIDS. As they see it, churches and faith-based organizations existed long before the AIDS epidemic, and they will be here long after. From World Relief's perspective, they are the best way to reach the most vulnerable members of society.

From Relevance to Revelation: Mobilizing the Church into Action

For World Relief, the first step in mobilizing churches is to create relevance. This is achieved through orientation and sensitization meetings that place HIV/AIDS within a broader context. By referring to specific passages in the Bible, church members become aware that care and support is part of their mandate to serve the needy.

World Relief guides church members through a series of steps that 1) highlight how HIV/AIDS relates to the Church's mandate to serve the needy, 2) enable church members to identify needs within the community, and 3) equip them with skills to develop sustainable solutions. Below are the specific stages.

Stage 1: Learning what action to take from the Bible

- Find out what the Bible says is the responsibility of the church towards the underprivileged (e.g., the poor, the sick, orphans, widows), and then look at the kind of people AIDS creates. Next, look at what the Bible says about the resources needed to be involved, what resources are available to people, and how to make a plan.
- Identify the resources that currently exist in the church, such as people, structures, ministries, and finances, to effectively respond to the HIV/AIDS epidemic.
- Discover the church's unique role and positioning to make a significant contribution to the fight against HIV/AIDS. Discover the opportunities HIV/AIDS presents to the church.

Stage 2: Give church members a list of assignments

- Get together with a few people from your church who consider working with people affected by HIV/AIDS their ministry, just as others prefer to teach Sunday school or preach. If the church is not ready for this assignment, their first assignment is to talk about AIDS in the church using the pulpit or any other ministry structures.
- In your immediate community (such as your church parish community), find five families with orphans and five families with a person living with HIV/AIDS.
- Record your observations about their circumstances. What are the major issues/problems? What are their needs? Which of those issues can the Church address without any external support?
- Go out and do what is feasible to address those issues (time frame: two months)

Stage 3: Sharing of experiences

After the two-month trial period, church members reconvene to share their experiences. Each participating church forms a ministry team to support the chronically ill and families affected by HIV/AIDS. Each team works with World Relief to determine the gap between what they are capable of doing and what they would like to do; the church may need financial and/or technical support. World Relief then assists in filling that gap by investing organizational resources.

Stage 4: Identify opportunities for generating and sustaining a resource base to continue the work

World Relief primarily serves as a facilitator/enabler during the above process. It first equips church members with information and skills to provide care and support services that are within their reach. The idea is to figure out what can be done without external financial support. World Relief then works with church AIDS and youth ministries to make efficient use of existing community resources and to incorporate low-cost, culturally appropriate techniques (e.g., dancing, drama) to promote key messages and mobilizing the larger community into action. Once gaps have been identified through practice, World Relief invests financial resources (in Malawi, these funds come primarily from U.S. church donations) into the ministries to bolster what they are doing.

World Relief addresses the stigma of PLHA and orphans due to HIV/AIDS first by working with the church leadership to look at what the Bible commands Christians to do. Next, World Relief and the church leadership together work to create a supportive environment that allows people living with HIV/AIDS to talk about their problems without the fear of being ostracized. Third, as the church members get involved personally in the lives of PLHA, they are less likely to stigmatize the individuals and families affected by the disease. In these ways, World Relief deals with stigma by focusing on the structures, attitudes, behaviors and systems that promote it.

World Relief has developed a number of manuals and audiovisual resources related to HIV/AIDS based on its activities in Malawi, Rwanda, and other countries. Below are examples of some of their materials.

- *Mobilizing for Life (video):* covers five modules-prevention education, care and support, church mobilization, agriculture/food security, and community empowerment
- *Facing AIDS Together (facilitator guide and training manual):* jointly developed with Freedom From Hunger (http://www.freedomfromhunger.org) to integrate HIV/AIDS efforts with micro-credit activities
- *Our Children (manual):* a how-to manual for churches interested in supporting orphans and vulnerable children; includes case studies
- *Living Hope for Africa (video):* a five-part video designed to guide churches in their discussion about HIV/AIDS and what they can do about the problem in their communities.
- *Choose Life (manual):* a guide to helping youth make wise choices
- *Hope at Home (manual):* a manual that sensitizes churches to AIDS and provides guidance on providing home-based care and support to PLHA and their families

Summary of Lessons Learned

- One of the keys to mobilizing communities around the needs of PLHAs and/or children and families affected by HIV/AIDS is to create relevance and a sense of responsibility.
- Before rushing to invest organizational resources, figure out what communities are capable of doing without external support. Communities have answers to their problems, and the role of the participating NGO can be to help the community explore, reflect, and put into practice these solutions. As a result, communities will develop a greater sense of ownership over the program.
- Organizations should assist communities in the self-realization of their needs. Needs should be generated through practice, not imposed by outsiders.

- External resources should be used as leverage to release community resources, not to replace them. Because of this, it has been very important to allow the churches to do what they can do without any external help.
- The best and most sustainable way to meet the needs of orphans and other vulnerable children is to use structures and institutions that already exist in communities, such as churches, instead of building new structures that will require maintenance or that will dissolve once the program ends. The goal in dealing with OVCs should be their integration with the community-at-large, and the best way to achieve this goal is by using existing structures.
- Workshops need to be aimed at meeting the needs generated in the community by the program.

World Relief emphasizes integration of programs. For instance, orphans under the age of 5 go to church-based child development centers where they are taught biblical values, as well as how to read and write in preparation for school. Furthermore, they have the opportunity to socialize with children who are not orphans and to participate in an environment different than one they are typically in. To enable guardians to work in gardens away from home, the children are fed one meal. One child development center run by Holy Trinity Church is called Chisomo, which means "grace"; it is important to avoid calling the centers "orphan centers" to reduce the risk of further stigma and isolation of the orphans.

Youth clubs are also an example of integrated programming. Older orphans join these clubs also run by the churches partnering with World Relief as part of their Youth Ministry. In the clubs, the children participate in Bible study, sports, agricultural projects, community development projects, AIDS awareness, drama, and music. They also support the ministry teams in helping families affected by HIV/AIDS complete simple home chores. World Relief feels that such activities sensitize the children to the devastation caused by AIDS better than any seminar they might conduct. Currently, there are 10 youth clubs with an average of 50 youth members in each club.

For more information on World Relief's efforts to support orphans and vulnerable children in Malawi, contact Stella Kasirye at skasirye@hotmail.com, World Relief's Country Representative for Malawi. World Relief's headquarters is at 7 East Baltimore St., Baltimore, MD 21202; Tel: (443) 451-1900; e-mail: worldrelief@wr.org.

Case Study 4. Hope for PVO Partnerships? The Successes, Challenges, and Lessons Learned from the Hope for African Children's Initiative

The situation in this case study, the Hope for African Children's Initiative (HACI), differs from the others in that PVOs are attempting to work together to achieve results more effectively and more efficiently, building on the strengths of each organization. Although such a partnership has numerous potential benefits, it also brings many challenges, as the case study describes.

NGOs recognize that there is power in numbers. However, partnership is easier said than done. HACI (http://www.hopeforafricanchildren.org) offers an interesting case study on NGO collaboration. HACI was formed by five international NGOs-CARE, Plan International, Save the Children, the Society for Women and AIDS in Africa, and the World Conference on Religion and Peace-to strengthen the capacity of African communities to provide care and support to children and families affected by HIV/AIDS. Since its formation in 2000, HACI has expanded by leaps and bounds, but not without growing pains. This case study highlights some of HACI's successes, as well as important challenges and lessons learned with respect to PVO partnership.

The HACI Model

In 2000, HACI received a US $10 million planning grant from the Bill and Melinda Gates Foundation (http://www.gatesfoundation.org) to identify and expand cost-effective community-based programs that support children and families affected by HIV/AIDS. In the beginning, HACI focused on three countries (Kenya, Malawi, and Uganda) but has since expanded to six (the three additional countries are Cameroon, Mozambique, and Senegal). The partnership is in the process of expanding to seven more countries (Democratic Republic of Congo, Ethiopia, Ghana, Mali, Namibia, Tanzania, and Zambia).

HACI's secretariat is based in Nairobi, Kenya. There are additional coordinating mechanisms at both the global and country levels. At the global level, HACI operates through a Program Policy Council (PPC). The PPC provides technical guidance to HACI country initiatives and is responsible for advocacy and fundraising. At the country level, HACI operates through a Country Program Council (CPC). CPCs are responsible for developing country strategies, getting additional resources from bilateral and multilateral donors (e.g., The Global Fund), and disbursing small grants ($1,000 to $5,000) to local NGOs and CBOs. Within each country, the CPC selects one partner organization as the host agency. HACI hires staff and purchases vehicles, equipment, and other commodities using the management structure (e.g., salary scales, administration systems) of the host agency.

Through its advocacy efforts, HACI has helped to raise global and pan-African awareness regarding children affected by HIV/AIDS. The initiative has also obtained additional funding from bilateral and multilateral donors. This has enabled HACI to expand throughout sub-Saharan Africa.

HACI is also starting to include other international NGOs (e.g., World Vision) in the partnership. There are no set criteria for joining HACI, although two critical questions are considered: 1) What is the value added by including the new organization? and 2) What will the new organization gain from HACI? HACI also realizes that there will ultimately need to be a limit to the number of organizations that can get involved.

Challenges Faced by HACI

Many multi-agency initiatives make the mistake of identifying key people within each member organization and promoting cooperation between those individuals. The biggest challenge faced by HACI has been ensuring that the partnership exists in practice, not just in name. This not only applies to how HACI partners relate to each other, but the relationship between HACI partners and national NGOs. Fostering openness and trust has been a challenge.

HACI Board members are usually high-level managers (e.g., Vice Presidents) from the partner organizations. HACI has been fairly successful in getting Board members to work together. It has been much more difficult to facilitate collaboration and coordination between all departments and levels (e.g., headquarters, country programs) of the different organizations, primarily because those parties were not involved in the early stages of the partnership.

Another important challenge lies in minimizing unfulfilled expectations at the community level. Through its advocacy efforts, HACI has generated a tremendous amount of enthusiasm and demand, but it has not been able to meet all requests for funding. As a result, many CBOs have been disappointed.

Pushing Forward, Making Progress

As HACI grows, it is focusing attention on the following two dimensions that have not received due attention in the past:

- Mechanisms that facilitate identification, dissemination, and uptake of state-of-the-art and/or promising practices
- Better standardization across projects and countries (when appropriate).

To address the first issue, HACI will be forming Technical Exchange Networks at the following two levels:

- Pan-African: which will draw upon expertise from the global community
- Country-level: which will combine HACI partners with other individuals or organizations (public, private, nongovernmental, and educational) to identify best or promising practices within the context of a particular country.

HACI is also working on various toolkits and a standard set of indicators and guidelines for determining program effectiveness. The following are examples of toolkits that are in progress:

- Advocacy and communication toolkit: to guide implementers on the basics of advocacy (e.g., how to engage the media) and the development of behavior change strategies (e.g., how to conduct formative research and how to use the information to develop messages and strategies)
- Monitoring and evaluation toolkit: to provide guidance on how to gather information on issues related to orphans and vulnerable children; how identify outputs, outcomes, and impact; and how to set relevant indicators.

Summary of Lessons Learned

- An initiative with too many partner organizations can become unworkable. In selecting partners, it is important to minimize duplication of efforts and identify the unique strengths of each organization and the value added (for both the individual organization and the overall initiative) in joining the partnership.
- Collaboration among individuals is fairly easy. Collaboration between organizations is much more difficult. For a partnership to truly work, transparency (between and within organizations) is important. It is necessary to involve parts of organizations that seem peripheral from a program perspective (e.g., the Finance and Legal Departments)-not just high-profile managers or organizational leaders-in all stages of planning and action.
- Be realistic about how far the dollar can stretch, and be careful about creating unfulfilled expectations. Explore opportunities to link needy communities that do not receive financial assistance with organizations that can contribute non-cash resources. For example, HACI is now beginning to form partnerships with organizations that can contribute non-cash resources (e.g., the Heifer Foundation is donating cows) to needy recipients. This approach might also produce results that are more sustainable in the long term.
- To facilitate the sharing of experiences, tools, and approaches between countries and organizations, it is important to include budget line items for cross-country study tours and/or in-country mechanisms (e.g., monthly or quarterly sharing sessions, newsletters, site visits) that allow projects to share innovations, challenges, and lessons learned.

For more information about HACI, contact the HACI Secretariat at: P.O. Box 76224-00508, Nairobi, Kenya; Tel: +254-2-578246/578269, Fax: +254-2-577248.

HACI also has an office in the United States. Contact information is as follows: 1730 N. Lynn Street, Suite 600, Arlington, VA 22209; Tel: (202) 365-6786, Fax: (703) 807-1264.

VI. Are We Really Making a Difference? Monitoring and Evaluation Issues

NGOs have made enormous efforts to support children, families, and communities affected by HIV/AIDS. Many of them are beginning to consider scaling up what they are currently doing. However, before doing so, it is important to determine the effectiveness and impact of those interventions.

In recent years, there have been a number of M&E guides and manuals that relate specifically to HIV/AIDS. The majority of them are available on the Internet.

This section does not go into detail on how to establish an M&E system for a project serving children affected by HIV/AIDS. Instead, it highlights key considerations based on noted M&E challenges faced by many NGOs. The following challenges are addressed in this section:

- Identifying relevant and useful indicators
- Assessing quality of care/service delivery
- Designing approaches to assess the effectiveness or impact of interventions.

Historically, NGOs have demonstrated a commitment to working collaboratively with beneficiaries, communities, and other local stakeholders when designing and implementing programs. Organizations are encouraged to adopt a similar approach when developing their M&E strategies. Creating an M&E strategy in a transparent and participatory manner will help to ensure that the data generated by the project meet local information needs. By making project M&E relevant to how the community addresses the needs of vulnerable children, projects can facilitate the use of project data for improved decisionmaking. In other words, increased use of programmatically meaningful data can help maximize program results and impact.

VI.1 Identifying relevant and useful indicators

Widely used HIV/AIDS M&E manuals include basic indicators related to orphans and vulnerable children (see Table 2 for an illustrative list of indicators). However, most of the indicators do not reflect the breadth and depth of NGO initiatives.

With very little guidance on how to assess their interventions for children affected by HIV/AIDS, many NGOs have struggled with M&E issues. The following are key considerations for developing program indicators:

- **Establish clear and measurable program objectives—**One of the first requirements for developing a useful M&E system is the existence of clear and measurable program objectives that 1) reflect intervention activities and 2) are realistic given the time frame and resources available.
- **When considering indicators, think of the desired project outcomes—**Because NGOs are involved in a broad range of activities for children affected by HIV/AIDS, there are many possible outcomes. The following are two examples:

  A PVO child survival project is working in a set of communities severely affected by HIV/AIDS. An early assessment of the local context indicates that there are large numbers of children being cared for by grandmothers and older siblings (due to the death or chronic illness of the biological mother). Full immunization rates are extremely low (30%) in the target area, but there are major differences according to the type of caregiver. Only 5 percent of children with nonmaternal caregivers are fully immunized, compared to 77 percent of children whose primary caregiver is the biological mother. In light of this huge differential, as well as its limited resources, the PVO aims to improve full immunization coverage from 5 percent to 40 percent among children with nonmaternal

caregivers during the 5-year project period. It chooses to use the percentage of children aged 12–23 months who are fully immunized by the first birthday to determine whether this objective is met.

A local NGO conducts a population-based census of orphans and discovers that the overwhelming majority of them are not in school. As a result, it plans to work with communities and the education sector to establish community schools and create other special mechanisms for getting these vulnerable children to school. It aims to have 50 percent of targeted school-aged orphans in school within the next 3 years. It has identified the following indicator to determine whether that objective is met: the percentage of orphaned children aged 10–14 who are currently attending school.

Some results are more difficult to measure objectively than other results. At present, there are no internationally accepted indicators for psychosocial well-being or child welfare. However, it is possible to identify processes or intermediate outcomes that contribute to the desired results of a program. This topic is discussed further in the next section.

Table 2. Illustrative Global Indicators

- Percentage of children under age 15 who have lost either their mother, their father, or both parents (Purpose: To track trends in the orphan burden within the general population)
- Percentage of households currently caring for orphans and other vulnerable children that have received free external help (e.g., from neighbors, religious institutions, government agencies) with caring for the child (emotional, medical, school-related assistance, and other social support) (Purpose: To assess the extent to which family and community mechanisms provide for the needs of households with children orphaned and made vulnerable by HIV/AIDS)
- Ratio of orphaned children aged 10–14 in a household survey who are currently attending school to non-orphaned children the same age who are attending school (Purpose: To assess progress in preventing relative disadvantage in school attendance among orphans versus non-orphans)

NOTE: An international interagency working group has been working on an M&E guide specific to the issue of orphans and vulnerable children. The document will be available by the end of 2003.

- **Understand what you want to achieve through M&E—**A project's M&E results can tell many stories. In general, the information or data generated by the project can serve the following two purposes:
  1. To address the question of program effectiveness/impact (e.g., Are we really improving the outcomes of children affected by HIV/AIDS?)
  2. To assess processes that affect whether or not program objectives are met (e.g., Is what we are doing efficient, of high-quality, and contributing to our ultimate objectives?).

It is advisable to identify M&E indicators and activities that serve each of the above purposes. With the first purpose, the aim is to determine whether results predicted at the beginning of an intervention (which are expressed as objectives) were achieved by the end of the intervention. This is the evaluation aspect of M&E. The second purpose relates to the monitoring aspect of M&E. It is used to determine 1) how well program activities are being implemented (and to make adjustments, if necessary) and 2) whether progress is being made toward the desired result(s).

As an example, if an organization has a psychosocial or child well-being intervention, it might chose the following indicators:

- *For evaluation:* percentage of targeted children who report that they have someone to talk to when they have a problem or feel sad; percentage of targeted children who report being teased or mistreated at school because of their parent's death or illness; percentage of target beneficiaries who have not reported [examining baseline-final changes in indicators such as these can help to determine program effectiveness]
- *For monitoring:* number (or percentage) of households with orphans and other vulnerable children that have received at least one visit in the past 3 months by a psychosocial worker; percentage of targeted children participating in child-to-child support groups; number (or percentage) of teachers who have undergone initial or refresher training on the psychosocial needs of children affected by AIDS in the past year; percentage of teachers who can recognize signs of child maltreatment and abuse; number (or percentage) of targeted families affected by HIV/AIDS that have created memory books with their children.

NOTE: Whether an indicator is used as a process (monitoring) versus impact (evaluation) indicator depends on the program objective. For example, if the aim is to increase access to psychosocial services, the first monitoring indicator listed above could actually be used as an evaluation indicator.

- **Consider data sources, feasibility of data collection, and data quality/appropriateness—**It is important to give careful consideration to how project M&E data will be collected. For example, if your organization is interested in documenting certain issues related to orphans and other vulnerable children, a conventional household survey might miss vulnerable children in child-headed households, on the street, or in orphanages. Consider the appropriateness of both the tools and data collection methods, given the local context and the types of decisions that need to be made from the data. Data collection choices should also be based on whether high-quality (e.g., timely, complete, accurate) information can be collected. Due to the facts that 1) there is no such thing as perfect data, and 2) an organization might not have the amount of resources required to get optimal data, it might be necessary to accept certain biases. However, these limitations should be documented, and caution should be exercised when interpreting the information. To continue with the above example, if a PVO evaluates its options and determines that a household survey is the best option for collecting the information it needs, it will be important to 1) get a clear profile of the children included in the sample and 2) not extrapolate the survey findings to all vulnerable children.

NOTE: There is no need to "re-invent the wheel" when it comes to data collection tools. There are a number of surveys available on the Web that can probably be adapted to meet your organization's needs.

- **Recognize that all things are not quantifiable—**Indicators can provide a useful, objective, and quantifiable way of assessing projects. However, it is important to recognize that some issues (e.g., perceptions, socio-cultural norms) might not be easily quantified (or might not be quantified adequately). For those issues, organizations can use qualitative information gathering to supplement quantitative data. The choice of qualitative method depends on the type of information required, as well as on the setting. Most NGOs that do some form of qualitative information gathering rely on the following:

  - Focus group discussions
  - In-depth interviews
  - Key informant interviews
  - Observation of events or behaviors
  - Role playing and story completion
  - Mapping exercises.

There are a number of Web-based materials to assist organizations that are interested in gathering qualitative data. Sometimes NGOs use qualitative information gathering to explore problems that were highlighted in quantitative sources in greater depth. Others use qualitative information gathering when designing their quantitative data collection tools (e.g., surveys, checklists, or registers) to identify context-specific and/or culturally appropriate terms, concepts, or symbols. Others use qualitative information to track beneficiary perceptions of the quality of the services being delivered. All these applications are valid uses of qualitative data.

VI.2 Assessing quality of care/service delivery

HIV/AIDS is a dynamic epidemic, and its impacts are far reaching. In response to the magnitude and severity of the problem, the international community has focused primarily on extending the reach (coverage) of basic care and support interventions. As a result, very little attention has been paid to the issue of quality. Although increasing the number of vulnerable children who are reached by important services might yield some benefits, addressing quality issues can help to maximize and sustain the impact of those services.

At present, there are no international standards of quality of service delivery related to children affected by HIV/AIDS. This presents a challenge from an M&E perspective. Nevertheless, quality is an important dimension to consider. The following are illustrative scenarios.

If your organization is helping community members to establish a community-based child-care program, you might take into account the following:

- Number of trained service providers (e.g., teachers/caregivers, psychosocial workers) per child
- Whether hours of operation coincide with the times care is needed
- Availability of first-aid or basic child health (e.g., oral rehydration solution) supplies
- Safety or cleanliness of building/infrastructure
- The degree to which children's needs are being addressed holistically.

If your organization is working with local stakeholders to establish community schools, you might consider the following:

- Competence of teachers/instructors
- Number of teachers per child
- Safety/cleanliness of classrooms (educational environment)
- Availability of school supplies (e.g., books, writing materials)
- Quality of the curriculum compared to that of the formal school system
- Appropriateness of times of operation (e.g., if most street children or child heads of households work during the day, then a community school that only takes place during the day will miss a large portion of its target group).

In a program addressing the psychosocial needs of children affected by AIDS, you might want to think about the following:

- Competence of psychosocial care providers in diagnosing and addressing children's needs
- Referral rate for psychosocial or child welfare services (e.g., if school teachers are trained to refer vulnerable or abused children for special support services, you might assess the proportion of teachers who know the 1) signs of child abuse or maltreatment and 2) administrative procedures for referring abuses/maltreated children to the appropriate services)
- Missed opportunities for child psychosocial support (e.g., through home-based care networks).

VI.3 Designing approaches to assess the effectiveness or impact of interventions

Selecting the appropriate indicators and data collection methods might help an organization to determine whether the project has met its objectives, but it will not shed light on whether results can be attributed to the project's interventions versus other factors. Evaluation designs are therefore important to consider when designing your program activities.

The issue of cause and effect has not been addressed extensively in the NGO community. However, there are a number of basic evaluation options for assessing program effectiveness and impact.

To make convincing statements about program impact, it is important to identify control or comparison groups. Most NGO staff are familiar with quasi-experimental designs. By comparing two sets of populations or communities that are similar in most regards EXCEPT exposure to your intervention, it is possible to determine whether any changes in key outcomes over time can be attributed to your project activities or whether those changes would have occurred anyway. It is important to note that selection of comparison groups is not based on an "all or none" principle. The group might be exposed to other interventions, just not the one your organization is interested in evaluating.

Ideally, comparison groups should be identified when designing an intervention. If it is not possible to do so, the following are the next best options:

- *Pre- and post-intervention comparisons:* Most projects conduct a pre-intervention assessment to identify needs and set objectives, then evaluate the effectiveness of their interventions by comparing an end-of-project estimate to those objectives.
- *Time Series:* With a time-series design, mini-assessments are made throughout the life of an intervention. This approach enables project staff to modify program activities and improve service delivery (if necessary) to achieve the desired end results. It also enables you to track gradual changes in key outcomes within your target population over time.

VI.4 What about cost?

NGOs are encouraged to use sound M&E practices to identify which intervention activities are most effective in producing positive outcomes for children affected by HIV/AIDS. However, it also important to consider the costs required to bring about those outcomes. Very few projects conduct cost analyses, even though the issue of cost-effectiveness can have major implications in terms of going to scale and sustainability. Cost analyses are therefore an important aspect of project M&E, and organizations should consider the requirements for cost analyses when designing their interventions.

At a minimum, it is important to determine the cost of the intervention per beneficiary (Total cost of the intervention/Total number of targeted child beneficiaries). Although this is not a measure of cost-effectiveness, it is a starting point. The following are important question to consider:

- What are the outcomes/results you are trying to achieve?
- What are the costs associated with achieving each of those outcomes/results?
- Where will you get information on cost?
- How will you get information on cost?

As with any assessment, the following questions will need to be answered:

- What types of data are required?
- Who will collect the data?

- When/how often will the data be collected?
- What data collection tools will be used to collect 1) the cost data and 2) the outcome/result data?

See Section VIII.2 for links to Web-based resources that provide additional information on cost and cost-effectiveness analyses.

VII. Taking Effective Approaches to Scale

VII.1 Deciding whether to scale up your program

There is now tremendous pressure for programs and services that address the needs of children affected by AIDS. The rapidly increasing numbers of children are obvious to all concerned, and this results in calls for a rapid scale-up of effective approaches. Many of the small organizations that are working with children affected by HIV/AIDS are being told to "think big" and plan to cover as large an area as possible when they apply for funding from donor agencies.

Most NGOs will focus primarily on scaling out. In other words, they gradually increase the number of individuals, families, communities, etc. served; add supplementary services for a more comprehensive or integrated approach; expand the geographic reach of services (e.g., expanding to a neighboring district); and strengthen the capacity of NGOs, CBOs, FBOs, VACs, etc. to respond to local needs. With time, and with the sharing of lessons learned and successful models of care and support for children affected by HIV/AIDS, NGOs can help create an effective mechanism for scaling up (i.e., expanding proven and effective programmatic responses by implementing agencies; regarded as being more "top down" and driven by external agents [e.g., donors, international organizations]).

There are a number of child survival interventions that have been implemented on a sub-national or national scale. These include oral rehydration therapy for diarrhea, routine immunization, and treatment of pneumonia outside of health facilities by community health workers. Rapidly going to scale sounds very attractive, and international experts often encourage it. However, NGO program managers need to be aware of the common challenges and pitfalls associated with previous attempts at going to scale. It is extremely important to consider whether it makes sense to try implementing at scale, and if so, then when, how, and by whom. This section raises some important issues to take into account.

The following field snapshot highlights Project Concern International's (PCI) expansion efforts in Lusaka, Zambia. It illustrates the point that NGOs can make contributions even when they are not directly implementing services. Local capacity strengthening is actually a part of going to scale.

Field Snapshot 6. PVOs as Facilitators and Enablers

In Lusaka, Zambia, PCI has not limited its vision to just expanding its own program efforts. Instead, it has worked with Zambian groups in Lusaka that support children affected by HIV/AIDS. In 2000, PCI and a local partner, Fountain of Hope, formed AfricaKidSAFE (Shelter, Advocacy, Food, Education). AfricaKidSAFE is now a network of 10 local NGOs and CBOs that address the needs of thousands of vulnerable children (e.g., street children) in Lusaka daily.

PCI's experience with AfricaKidSAFE suggests that international NGOs can serve as facilitators or enablers to expansion, not just as direct implementers of programs. PCI has assisted local organizations to tap into international donor resources. It has also provided technical guidance to their programs, and through AfricaKidSAFE, it has created a forum for small-scale, local efforts to share resources, innovations, and lessons learned, as well as bring greater visibility to their work.

PCI's experience in Zambia has also highlighted that bringing visibility and additional resources to local NGOs and CBOs is not enough. There also needs to be a commitment to transparency and strengthening the organizational capacity of those organizations (e.g., working with staff on budgeting/financial management, resource mobilization and allocation, goal setting, planning, and monitoring and evaluation).

For more information on this program, contact PCI at 3550 Afton Rd., San Diego, CA 92123; Tel: (858) 279-9690; fax: (858) 694-0294; or e-mail them at postmaster@projectconcern.org.

There is no clear-cut formula on how to take an intervention to scale. However, when one examines interventions that have been successfully taken to scale, there are some patterns. The following factors are usually present:

- *Appropriate selection of interventions*—Typically a narrower set of interventions is implemented when a program is taken to scale than when it is implemented in only one or a few communities. It is important that the right set of interventions be selected so that the program can remain effective as it is scaled up.
- *Enabling environment*—Political will, socio-cultural norms and sanctions, and multi-sectoral partnership create an environment that supports the implementation and expansion of particular programs or interventions.
- *Documentation*—Implementation steps and processes are clearly documented (in the form of guides, manuals, and training materials) to ensure that others can reproduce the intervention.
- *Mechanisms to ensure quality*—Mechanisms to ensure quality of service provision exist, and they are maintained as the intervention is taken to scale.
- *Definition of expected roles*—There is clear consensus between the community, local government, and other stakeholders in terms of their expected roles, responsibilities, and inputs as the program expands.

The remainder of this section discusses each of the above factors in more detail. We have presented a checklist of issues that your organization should think about in preparation for taking a program that addresses the needs of children affected by HIV/AIDS to scale.

VII.2 Appropriate selection of interventions

It is essential to understand what components of the intervention are necessary to produce the desired end results and what components are helpful but can be omitted without compromising effectiveness. Inevitably, when programs are scaled up, a narrower and more focused set of interventions needs to be

selected. In addition to supporting efficient service provision to a larger group of beneficiaries, a narrower set of interventions reduces the average cost per beneficiary-a crucial step in preparing to take a program to scale. Before taking an intervention to scale, do the following statements apply to your project?

- We have systematically determined that the interventions we would like to expand have the greatest impact on vulnerable children and families in AIDS-affected communities in the local context.

Next steps if your organization has not met this criterion:

- Make sure that your organization has identified a set of indicators that adequately reflect what you are doing and that match a set of results that are measurable.
- Use operations research to test different models of service delivery or specific intervention components.
- We have adequately explored ways to reduce the cost per beneficiary. The project has conducted a cost/cost-effectiveness analysis of the intervention(s).

Next steps if your organization has not met this criterion:

- Assess the costs associated with each element of the intervention you would like to bring to scale; determine cost-effectiveness
- Identify areas where costs can be reduced (e.g., reducing the number of paid staff; obtaining donated land [from the government, village chiefs, etc.] or buildings rather than paying rent; identifying supplies that can be made or purchased locally rather than purchased elsewhere; determine to what degree community members can contribute (e.g., material support [donated food, clothing, school fees or supplies])

VII.3 Enabling environment for the program

An enabling environment for the program or intervention may include 1) official policy statements in support of the program and/or its aims, 2) steps taken by participating organizations to reduce stigma among community members, service providers, and others, and 3) commitment by government and other organizations to providing some support for implementation either financially (which will often be impossible) or by contributing existing human or material resources.

- We find that there are official policy statements in support of the program and/or its aims.

Why are official policy statements needed? When organizations are working in only a few communities, their work might not be on the "radar screen" of government. When they seek to implement programs at scale, however, perceptions quickly change, and some officials may feel that the organization's activities are not in the best interest of the country. For this reason, prior to scaling up, organizations need to work at the national level (through advocacy activities) to create an environment that will enable an effective program to be implemented at scale.

Next steps if your organization has not met this criterion:

- Focus on advocacy with regional and national leadership to describe what your organization has accomplished so far, and gain support for your vision for scaling up the program.
- Partner with other PVOs, NGOs, and CBOs (There's power in numbers).
- We have addressed stigma, discrimination, and social protection issues. Have stigma, discrimination, and social protection issues been adequately addressed by:
- Government/political leadership (e.g., through laws, policies, national strategies, allocation of resources)?
- FBOs and other influential entities (e.g., Are religious leaders endorsing and facilitating care and support of individuals and families affected by HIV/AIDS)?

Next steps if your organization has not met this criterion:

- Focus on advocacy with local (e.g., regional, district) and national leadership to develop strategies and legislation that normalize HIV/AIDS and affected individuals.
- Engage traditional and religious leaders, teachers, political leadership, and other influential groups in awareness-raising activities; promote community dialogue (e.g., through skits, music, radio spots) to address myths and misperceptions regarding HIV/AIDS and promote a compassionate response to problems faced by PLHA, their children, and their families.

VII.4 Documentation

- We have adequate documentation and training materials so that others can easily learn our approach to implementation, as well as our challenges and lessons learned.

Documentation of your program may take the form of guides, manuals, and training materials, so that others can reproduce the intervention. Often the exact steps in implementation are in the heads of those who carry out the work in the field, but have yet to be formally written down. Recognizing this need, a number of NGOs have produced manuals and training materials in recent years. This means your organization does not have to start from the beginning, but can modify or build on these other manuals and materials.

Next steps if your organization has not met this criterion:

- Gather and review existing manuals and training materials produced by other organizations working with children affected by HIV/AIDS.
- Put your own approach down in writing, at least in draft form.
- Assess the need to produce your own manuals or training materials, versus using or adapting materials that already exist.
- Pre-test your materials systematically the first time you use them to expand your program to cover a new area.

VII.5 Mechanisms to ensure quality

Quality should be maintained as the intervention is taken to scale. Each organization needs to have the capacity to expand program efforts well, and to monitor their activities to ensure that they are being carried out with a high degree of quality.

- We have the organizational capacity to expand program efforts and do it well, as do many other implementing agencies (NGOs, CBOs, FBOs). For example:
- Systems for financial/administrative/program management are in place and functioning well.
- Attention has been paid to human resource issues (e.g., staff development, supportive supervision, incentives/disincentives, systems of accountability).
- Organizational vision, goals, and strategies are clearly defined.
- Approaches being promoted are sustainable.
- We have confirmed that there are established mechanisms to ensure that quality is maintained as efforts expand.

Mechanisms to ensure that quality is maintained as the intervention is taken to scale include systems of management and supervision put in place by an NGO or a local government, as well as community management boards, committees, and other forms of community oversight and engagement. It also entails setting up mechanisms for community members to interface with formal sector providers and officials.

If you will be relying more heavily on local NGOs, CBOs, and FBOs when taking the intervention to scale, there has been a transfer of skills in the following areas:

- Supportive supervision
- Logistics management
- Planning and resource allocation
- Financial management
- Mentoring and support in the accurate collection and timely use of routine data
- Volunteer support, incentives/disincentives
- Quality assurance measures are in place.
- We have confirmed that there is a system to ensure that field staff are not overburdened by the demands of implementation and that appropriate incentives are in place.

The overwhelming majority of community-based programs depend on the good will and commitment of volunteers. As NGOs develop and expand their efforts to support children affected by HIV/AIDS, it is important to identify issues related to volunteerism.

- We, in collaboration with local stakeholders, have developed clear mechanisms to support people who are assisting individuals, families, and communities affected by HIV/AIDS (e.g., through home-based care programs or orphans care and support) [See Field Snapshot 6].
- We have ensured that an appropriate system of incentives is in place. Money is not the only incentive. Some projects have used public recognition of volunteers using t-shirts, scarves, bus fare, etc. as ways to boost morale and maintain high retention and performance of volunteers.

Field Snapshot 7. Supporting Those Who Give Support

In Kenya, World Relief offers volunteers a "sabbatical," in which volunteers take vacation from their activities for an extended period of time. World Relief has also established volunteer support groups such as Faraja (which means "comfort" in Swahili). These two approaches have been critical to minimizing burnout and other negative outcomes associated with the physically and emotionally taxing nature of volunteer work, particularly in AIDS-affected communities.

For more information, contact World Relief at: 7 East Baltimore St., Baltimore, MD 21202; Tel: (443) 451-1900; e-mail: worldrelief@wr.org.

VII.6 Definition of expected roles

Without on-going local input, programs quickly run out of workers and resources as they expand, or they may not be responsive to changing local needs and priorities. These expectations may take the form of a statement such as "Our organization will work with your community and will be responsible for A and B, provided that the community and/or the local government provide C and D." Although the following example does not relate specifically to HIV/AIDS, it illustrates the above point.

There is a Community Health Agents (also known as community health workers (CHWs)) program in Ceará State, Brazil. When the program was officially initiated in 1989, there were approximately 35 participating municipalities with 1,500 CHWs. In 1998, there were more than 150 participating municipalities with more than 8,000 CHWs employed. (Svitone et al., 2000).

A unique aspect of the program, probably contributing greatly to its scaling up success, is the way it has been introduced into new municipalities. The State government will pay the CHWs' salaries, only if the

municipal government agrees to provide a salary for a nurse supervisor (Svitone et al., 2000). This scheme ensures local commitment before the government initiates the program in that area.

Commitment by a municipal government to pay salaries will not be applicable to the areas where AIDS is taking the greatest toll, but the idea of securing some form of local commitment to implementation is applicable. This local commitment might include contributing labor or materials for the construction or repair of a school, allocating land for backyard or community gardens, or assigning roles to local leaders in supporting and overseeing the program.

- We have reached consensus with communities regarding their roles and responsibilities as the program moves into new localities.
- Have you determined what communities can do for themselves? Rather than create a dependency on international assistance and material support, have you worked with communities to actively determine (through trial and error, determining needs through practice) ways that they can provide support to orphans and other vulnerable children and/or PLHA and their families? It is important to first identify their strengths, and then build on those strengths.
- We have reached consensus with local government and other stakeholders regarding their roles and responsibilities as the program moves into new localities.

Guiding principles for choosing what to bring to scale:

- To the greatest extent possible, work through existing structures to develop solutions.
- Families and communities are the first line of response.
- Strengthen extended families to absorb future shocks (e.g., additional orphans).
- FBOs and CBOs will most likely be there long after your organization has left.
- Interventions that are being brought to scale should be of proven effectiveness/impact.
- Establish mechanisms to maintain quality as efforts go to scale.
- Do not overstretch the community's capacity to cope.
- Your efforts should not undermine community initiative and motivation.

VIII. Conclusion and Additional Resources

VIII.1 Conclusion

It is very easy to feel besieged by the HIV/AIDS pandemic and the challenges that have arisen from it. However, we should acknowledge the fact that NGOs have played, and can continue to play, critical roles in mitigating the impact of HIV/AIDS on children, families, and communities.

With so much to be done, where do we go from here? We hope that this paper sheds light on how to be more systematic in addressing the needs of orphans and other vulnerable children in AIDS-affected societies. Rather than re-invent the wheel, you are encouraged to build on the strengths and lessons learned from decades of NGO experience. It is also important to stay true to the internationally accepted guiding principles for working with orphans and other vulnerable children.

At times, we might feel overwhelmed by the sheer magnitude of need. There is certainly a sense of urgency in most of our initiatives. But remember: how we plan, implement, evaluate, and expand our interventions is as important as what we implement. Through coordination of our efforts and on-going documentation of our experiences, NGOs can lead the movement to provide holistic support that promotes psychological healing and improved health, social, and economic outcomes. Helping children, families, and

communities to help themselves can ensure that those positive impacts are sustained well into the future. Every NGO initiative, no matter how small, has the potential to foster hope and a sense of self-determination in our most vulnerable members of society. Every child is deserving of that right.

VIII.2 For Further Information

Statistics and General Information

Children on the Brink 2002: A Joint Report on Orphan Estimates and Program Strategies. USAID <http://www.synergyaids.com/documents/COB2002.pdf>.

USAID Projects Profiles: Children Affected by HIV/AIDS. USAID <http://www.usaid.gov/pop_health/aids/Publications/docs/cabaprofiles.pdf>.

HIV/AIDS Virtual Resource Center for NGOs <http://www.childsurvival.com/vrc>.

Advocacy/Policy

Advocacy in Action: A Toolkit to Support NGOs and CBOs Responding to HIV/AIDS. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/index_eng.htm>.

An Introduction to Advocacy. SARA Project <http://sara.aed.org/publications/cross_cutting/intro_advocacy/intro_Advo_full%20(eng).pdf>.

HIV/AIDS Policy Compendium Database. POLICY Project <http://209.27.118.7/>.

HIV/AIDS Toolkit: Measuring Political Commitment. POLICY Project <http://www.policyproject.com/pubs/toolkit.html>.

Policies for Orphans and Vulnerable Children: A Framework for Moving Ahead. POLICY Project <http://www.policyproject.com/pubs/generalreport/OVC_Policies.pdf>.

Strategic Management Tools to Support HIV/AIDS Policy Change. <http://www.synergyaids.com/files.fcgi/3200_HIVAIDS_Policy_Change.pdf>.

Funding/Resource Mobilization

Raising Funds and Mobilizing Resources for HIV/AIDS Work. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/index_eng.htm>.

Learning Through Practice: Integrating HIV/AIDS into NGO Programmes: A Guide. The Policy Project <http://www.policyproject.com/pubs/NGOBooklet/SA_NGO_Booklet.pdf>.

Going to Scale

Expanding Community-based Support for Orphans and Vulnerable Children. International HIV/AIDS Alliance <http://aidsalliance.org>.

Expanding and Strengthening Community Action: A Study of Ways to Scale Up Community Mobilization Interventions to Mitigate the Effect of HIV/AIDS on Children and Families. USAID's The Displaced Children and Orphans Fund <http://www.dec.org/pdf_docs/pnacl778.pdf>.

Svitone, E. C., and R. Garfield, et al. 2000. Primary health care lessons from the northeast of Brazil: the Agentes de Saude Program. *Rev Panam Salud Publica*, 7, 293–302.

Monitoring and Evaluation

Indicators/General M&E

USAID Handbook of Indicators for HIV/AIDS/STI Programs. USAID <http://www.synergyaids.com/documents/1570_entiredoc.pdf>.

National AIDS Programs: A Guide to Monitoring and Evaluation. UNAIDS <http://www.unaids.org/publications/documents/epidemiology/surveillance/JC427-Mon&Ev-Full-E.pdf>.

Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries: A Handbook for Program Managers and Decision Makers. IMPACT <http://www.fhi.org/en/aids/impact/impactpdfs/evaluationhandbook.pdf>.

Survey Tools

Knowledge Practices and Coverage Survey (KPC2000+), HIV/AIDS Module. Child Survival Technical Support Project <http://www.childsurvival.com/kpc2000/kpc2000.cfm>.

Child Needs Assessment Tool Kit. World Bank, CDC <http://www.worldbank.org/children/cnahome.html>.

HIV/AIDS Survey Library. HORIZONS <http://www.popcouncil.org/horizons/AIDSquest/index.html>.

Orphans and Vulnerable Children Baseline Survey, Zambia. SCOPE and Family Health International <http://www.popcouncil.org/horizons/aidsquest/instruments/FHI-%20OVC%206-12,%20Zambia.pdf>.

World Vision/South Africa Orphans Survey. World Vision. Contact Monika Holst < monika_holst@wvi.org> for additional information.

Cost Effectiveness

The International AIDS Economics Network. IAEN <http://www.iaen.org/>.

Cost Analysis in Primary Health Care: A Training Manual for Programme Managers. World Health Organization <http://www.who.int/dsa/cat98/prim8.htm#Cost Analysis>.

Qualitative/Ethnographic Research

Rapid Rural Appraisal/Participatory Rural Appraisal. Catholic Relief Services <http://www.catholicrelief.org/what_we_do_overseas/RRA_Manual.pdf>.

Operations Research

Designing HIV/AIDS Intervention Studies. Population Council <http://www.popcouncil.org/horizons/orhivaidshndbk.html>.

Making a Difference for Children Affected by AIDS: Baseline Findings from Operations Research in Uganda. Population Council and Makerere University <http://www.popcouncil.org/pdfs/horizons/orphansbsln.pdf>.

Need-Specific Programming

Economic/Material

Building Blocks: Economic Strengthening. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Building_Blocks/English/Economic.pdf>.

Education

Building Blocks: Education. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Building_Blocks/English/Education.pdf>.

Health and Nutrition

Building Blocks: Health and Nutrition. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Building_Blocks/English/Health.pdf>.

Psychological/Emotional

Building Blocks: Psychosocial Support. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Building_Blocks/English/Psychosocial.pdf>.

Building Blocks: Social Inclusion. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Building_Blocks/English/Social_Inclusion.pdf>.

Safety/Social Protection

Building Blocks: Social Inclusion. International HIV/AIDS Alliance <http://www.aidsalliance.org/_docs/_languages/_eng/_content/_3_publications/download/Building_Blocks/English/Social_Inclusion.pdf>.

Program Design

Building Blocks: Africa-wide Briefing Notes. International HIV/AIDS Alliance (available in Portuguese and French) <http://www.aidsalliance.org/_docs/index_eng.htm>.

Filling the Gaps. Using a Rights-Based Approach to Address HIV/AIDS and its Affects on South African Children, Youth, and Families. <http://web.uvic.ca/iicrd/graphics/filling%20the%20gaps%20web.pdf>.

Learning Through Practice: Integrating HIV/AIDS into NGO Programmes: A Guide. The Policy Project <http://www.policyproject.com/pubs/NGOBooklet/SA_NGO_Booklet.pdf>.

Special Initiatives, Task Forces, and Interest Groups

Children Affected by AIDS Online Forum <http://www.synergyaids.com/Caba/cabaindex.asp>.

The International AIDS Economics Network. IAEN <http://www.iaen.org/>.

The Orphans and Vulnerable Children's Task Force <http://groups.yahoo.com/group/ovctaskforce/>.

IX. Appendices

Table A. Needs and Desired Results Related to Children, and Illustrative NGO Activities

NEEDS	DESIRED RESULTS	ILLUSTRATIVE NGO ACTIVITIES
1. Psychosocial		
Social integration	Children affected by HIV/AIDS are not socially isolated from other children or community members	• Develop sports and recreation activities to engage youth creatively and promote social integration of orphans and vulnerable children in the community • Work with community leaders to create apprenticeships for orphans and other vulnerable youth
Assistance coping with parental illness/loss	Children affected by HIV/AIDS have an outlet to express their feelings, thoughts, and emotions, and they receive psychosocial support from the community	• Train social workers, teachers, or other community members to provide psychosocial support to affected children, and address broader issues of stigma and discrimination against PLHA/their families • Develop mechanisms for youth-to-youth counseling and support • Work with PLHA/chronically ill parents and their children to: - Address psychosocial issues (e.g., using "memory books") - Engage in succession planning (e.g., preparation of wills, making guardianship arrangements, inheritance issues) - Building on traditional mechanisms/structures for caring for the needy, establish and/or strengthen a home-based care network for the chronically ill and their children (e.g., mobilize church members to volunteer and commit to regular household visits and/or orphan support activities) • Work with communities and district officials to form local AIDS committees that include a cross-section of the community (e.g., traditional/religious leaders, CHWs, PLHA, youth, private sector) • Through social and behavioral change strategies, work to create a supportive, stigma-free environment in which PLHA can disclose their status (e.g., form post-test clubs, PLHA support groups) and receive adequate support • Provide special support to youth heads of households or children/youth who are responsible for caring for siblings, sick/elderly family members, etc.

Table A. Needs and Desired Results Related to Children, and Illustrative NGO Activities *(Continued)*

NEEDS	DESIRED RESULTS	ILLUSTRATIVE NGO ACTIVITIES
2. Health- and Nutrition-related		
Quality child care, health care, and nutrition	Comparable health/nutrition status between orphans and non-orphans	• Develop specific strategies and messages that target nonmaternal caregivers (e.g., grandmothers or older siblings caring for orphans) on health promotion, disease prevention (e.g., immunization, hygiene/sanitation), and appropriate management of sick children • Develop HIV prevention activities targeting vulnerable youth • Work with the health sector to modify Integrated Management of Childhood Illnesses case management protocols (e.g., adapt IMCI guidelines to correctly manage children with symptomatic HIV) • Establish community-based child day care programs for needy children • Work with the education and health sectors to establish school feeding programs • Mobilize religious organizations, traditional/community leaders, and others to develop a community-based system of distributing food aid to needy families • Work with communities, Department of Agriculture, and other local stakeholders to improve food security of AIDS-affected families • Promote community or backyard gardens to produce nutritious foods and generate income that can benefit vulnerable households • Improve crop varieties and cropping methods appropriate to the labor capacities of households affected by HIV/AIDS • Address issues of intra-household food distribution (e.g., less food given to girls/orphans/foster children compared to others in the household)

Table A. Needs and Desired Results Related to Children, and Illustrative NGO Activities *(Continued)*

NEEDS	DESIRED RESULTS	ILLUSTRATIVE NGO ACTIVITIES
3. Educational		
Access to education	Orphans and other vulnerable children attend and complete school in similar proportions to other children of similar age	• Work with communities and the education sector to create community schools or introduce other innovations to deliver education to children who are not in school • Raise awareness among traditional and religious leaders, household heads, etc. about the importance of vulnerable children, in particular girls, attending school • Encourage families to obtain and retain important documents required for school enrollment (e.g., immunization card, birth certificate) for all children • Adapt school curricula to make them more relevant to children affected by HIV/AIDS (e.g., incorporate life-skills training, peer-counselor training) • Train teachers and school officials on issues related to HIV/AIDS prevention, care, and support, including ways to reduce stigma and discrimination in schools. Sensitize them to the special needs of orphans and other vulnerable children. • Work with communities to establish community savings plans that can be used to pay for orphans' school fees
4. Economic/Material		
Food, Shelter, Clothing	Economic status of households affected by HIV/AIDS is maintained, if not improved Households with orphans are able to afford to send all children to school Orphans and other children in vulnerable families have comparable nutritional status to children in other families	• Link initiatives supporting child-headed households, households with orphans, and/or households with chronically ill adults with income-generation activities being provided by other sources • Offer vocational training, apprenticeships, or other skills-building/income-generation opportunities to orphans and other vulnerable youth • Partner with MFIs to increase access to credit among widows, older youth, and other vulnerable individuals/households in AIDS-affected communities • Link families affected by HIV/AIDS with external assistance and support services offered by the government (e.g., grants to households with orphans; school-fee waivers for orphans) • Mobilize community members to provide material support (e.g., blankets, clothing, food, school fees, shelter) to vulnerable families • Address food-security issues faced by vulnerable families • Work with communities to establish community savings plans (e.g., to pay for funerals, school fees of orphans) or funeral clubs

Table A. Needs and Desired Results Related to Children, and Illustrative NGO Activities *(Continued)*

NEEDS	DESIRED RESULTS	ILLUSTRATIVE NGO ACTIVITIES
5. Safety/Social Protection		
Protection from exploitation or mistreatment (e.g., physical/sexual abuse, prostitution, being recruited as child soldiers, street children)		• Work with community leaders and members to establish orphans and other vulnerable children surveillance systems • Establish or strengthen referral between different sectors (e.g., health, education, social welfare, law enforcement) to ensure that vulnerable/abused/exploited children are linked with services that are appropriate for their circumstances • Train HBC volunteers to identify vulnerable children in the households that they visit, and refer them to appropriate support services • Train social workers and other individuals from the community to provide outreach to street children • Mobilize traditional and religious leaders and others in the community around gender discrimination and other gender-related issues
6. Cross-cutting		
Increased length of the parent-child relationship	PLHA live longer, better-quality lives	• Increase PLHA access to anti-retroviral therapy (ARV) (e.g., issues of cost, drug availability, referral mechanisms between counseling and testing and treatment/care and support) • Improve prevention and treatment of opportunistic infections (OI) in PLHA • Work with churches and other religious organizations to establish home-based care or AIDS ministries • Train family members in care-giving practices for PLHA • Teach students the basics in home-based care and support • Mobilize community members to assist households with chronically ill members in household chores/tasks • Integrate the needs of children affected by AIDS (including HIV+ children) into broader community-based efforts providing care and support to PLHA • Promote technologies that save time and labor in households with chronically ill members • Build local capacity in the nutritional management of HIV • Teach caregivers or household heads how to address the special needs (emotional, physical, etc.) of orphans and other vulnerable children

Table A. Needs and Desired Results Related to Children, and Illustrative NGO Activities *(Continued)*

NEEDS	DESIRED RESULTS	ILLUSTRATIVE NGO ACTIVITIES
6. Cross-cutting *(Continued)*		
A political and social environment that supports child well-being and protects the rights of individuals affected by HIV/AIDS	National policies, laws, and strategies exist that protect children, PLHA, and other vulnerable members of society Communities are aware of the special needs of children and families affected by HIV/AIDS and demonstrate compassionate responses Stigma and discrimination against LHA and their families is minimized	• Engage in advocacy with policymakers and program planners for the following: - Child protection laws - Property rights for widows, orphans (to retain family property should the husband/father die) - Educational access for all - Improving health service access, coverage, and delivery mechanisms - Guardianship and inheritance issues - Appropriate adoption and foster care - Prevention of inappropriate placement of children affected by HIV/AIDS in orphanages, children's homes, etc. - Anti-HIV discrimination laws (e.g., workplace policies) • Through social and behavioral change (SBC) interventions, facilitate changes in traditional practices that might promote the spread of HIV • Through SBC interventions, reduce stigma and discrimination directed at PLHA and their families • Facilitate participatory learning and action, or other participatory activities that engage community members in dialogue, raise awareness about the needs and rights of children and families affected by HIV/AIDS, and assist communities in setting priorities and organizing responses • Build local organizational capacity (e.g., local NGOs, CBOs) to respond to the needs of children affected by HIV/AIDS adequately and appropriately

Table B. Advantages and Disadvantages of Different Targeting Approaches

TARGETING APPROACH	TARGETING CRITERIA	MAJOR ADVANTAGES	MAJOR DISADVANTAGES
Focus on All Vulnerable Children.	STEP 1: Select communities with disproportionately large numbers of poor households. STEP 2: Within each community, target services/benefits to all needy and vulnerable children, whether orphan or not.	• Stigma is not as big a problem with this approach as with others. • Likely to reach children who really need support, and exclude those who really do not.	• Might stretch resources to thin to have an impact. • Organizational and/or local capacity might not be strong enough to implement such a large-scale program.
Focus on Both Single and Double Orphans.	STEP 1: Select communities with disproportionately large numbers of poor households. STEP 2: Within each community, target services/benefits to all households with one or more orphans (single or double).	• Concentrates resources on children/families that may be more vulnerable than others.	• Poor families that do not have orphans will be excluded. • Some communities may inflate the numbers of orphans to receive assistance. • Within households, it might widen the gap between orphans and nonorphans because benefits might not go directly to the orphan. • Using this approach, some households with orphans that don't really need assistance might become beneficiaries. (This risk is probably very low in predominantly poor communities).
Focus on Double Orphans Only.	STEP 1: Select communities with disproportionately large numbers of poor households. STEP 2: Within each community, target services/benefits to only those households fostering double orphans.	• Further concentrates limited resources on the most vulnerable children and families.	• Some communities may inflate the numbers of orphans in order to receive assistance. • Families that have single (maternal) orphans may be equally deserving of services and benefits, but would be excluded. Other vulnerable children with both parents alive would also be excluded. This might create resentment or adverse incentives.

THE CHILD SURVIVAL TECHNICAL SUPPORT PROJECT